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Family processes and coping strategies of families of adolescents diagnosed with epilepsy

by

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Declaration

I, Karlien Erasmus, declare that this thesis is my original work except where I used or quoted another source, which has been acknowledged.

I further declare that the work I am submitting has never been submitted before for another degree to any other university or tertiary institution for examination.

Signature: KErasmus
Date: **April 2019**

Abstract

Families with an adolescent diagnosed with epilepsy employ strategies to cope with the diagnosis. Critical realism, family systems theory and a mixed methods research design were utilized to acquire an enhanced understanding of the processes and experiences of these families. The McMaster and Circumplex models of family functioning were also applied. Through a process of informal discussions with neurologists and a review of the literature, aspects of family relational support were identified as an under researched topic. The purpose of this study was to explore family processes and coping strategies. Accordingly, family process profiles, in particular, family satisfaction, functioning and hardiness, as reported by patients and family members, were assessed by means of biographical information and standardized measuring instruments. Furthermore, interviews were conducted and Graphic Family Sculpting administered to explore the experiences of these families. The sample comprised 15 families of adolescents with epilepsy. Quantitative results revealed that male patients coped better than female patients and younger patients had lower adaptability skills and family satisfaction than the older cohort. The patients generally functioned better than their families. Qualitative results showed that epilepsy affects both family members and patients; furthermore, they have a need for support in family relational aspects and knowledge about epilepsy. The mixed methods results revealed that the quantitative and qualitative data complemented each other and created a sense of convergence. Support for these patients, families, meaningful others and treating medical specialists, may assist South African adolescents and their families to function optimally and cope better with their diagnosis.

Keywords: Adolescents with epilepsy, family processes, family process profiles, family satisfaction, family functioning, family hardiness, coping strategies, semi-structured interviews, thematic analysis, Graphic Family Sculpting

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CHAPTER 1: INTRODUCTION

In this chapter, the background of the study, statement of the research problem, purpose and significance of the study, definition of terms, research questions and overview of the study are provided.

1.1 Background, Motivation and Rationale of the Study

The effects of epilepsy on adolescents and their parents have long intrigued psychological researchers. The existing literature has revealed that there is an association between how parents cope with the diagnosis and how an adolescent patient subsequently copes with the diagnosis (Jones & Reilly, 2016; Rodenburg et al., 2013). The parents' reaction and coping as well as how adolescents cope seem to play a significant role in the functioning and emotional process of adjustment of adolescents diagnosed with epilepsy (O'Toole et al., 2015; Ryu, Lee, Eom, & Kim, 2015).

In this study, the family processes and functioning of 15 families with an adolescent diagnosed with epilepsy are explored. The participants included family members of adolescent patients who were receiving epilepsy treatment from a neurologist at a private medical facility in Tshwane, South Africa. The informal discussions the researcher held with neurologists revealed that it could be challenging to treat adolescents diagnosed with epilepsy. It may be difficult for these adolescents to cope with the diagnosis and furthermore, adolescents experience their own particular challenges.

Existing literature has focused on the reaction and challenges that the adolescent with epilepsy faces as well as the emotional effect epilepsy has on parents (O'Toole et al., 2015; Ryu et al., 2015). The researcher found limited research on the processes and functioning of the family. The researcher, as a practising psychologist, has observed in her medical-related work that the family and its processes and functioning play an important role in how patients deal with their medical conditions. The researcher has noted that with referrals of patients for psychological support in relation to a medical condition, family interactions and challenges become part of the topics dealt with during psychotherapy. Accordingly, the researcher decided to explore the family processes and functioning of families with adolescents diagnosed with epilepsy so as to explore the impact of the diagnoses on these processes and functioning, and thus, gain more insight into how family processes and functioning influence how these families deal with the diagnosis of epilepsy.

1.2 Research Problem and Question

Adolescence poses challenges to a family because more conflict with parents and authority figures, moodiness and high-risk behaviour may ensue (Cohen, Tottenham, & Casey, 2013). Over and above these challenges, the diagnosis of epilepsy in an adolescent has an emotional and physical impact on the patient as well as the patient's family (Appleton & Gibbs, 2014; Khan, Baheerathan, Hussain, & Whitehouse, 2013). First, the experience of an epileptic seizure is in itself a traumatic experience for patients and their families. Second, the confirmation of the diagnosis of epilepsy has a further emotional impact. These families are likely to experience certain processes and will consequently try to cope with the diagnosis by applying certain coping strategies. Ryu et al. (2015) demonstrated that the family environment is predictive of the psychological wellbeing of adolescents with epilepsy.

It appears, from discussions held with neurologists in private practice and research done on this topic that there is a need for emotional support for adolescent patients diagnosed with epilepsy and their families (Brown, Talbot, Simpson, & Whitehouse, 2012; Duim, personal communication, 2014, 2015, 2016, 2017; Güldenpfennig, personal communication, 2014; Mahne, personal communication, 2014; Noble, Morgan, Virdi, & Ridsdale, 2013). A plethora of research has been conducted on the psychological and emotional effects on adolescent patients diagnosed with epilepsy as well as the impact on their parents and siblings (Austin & Caplan, 2007; Camfield & Camfield, 2007; Mu & Chang, 2010; Solomon & McHale, 2012). It appears as though there is a gap in the research on the emotional impact on and roles of the family of adolescent patients diagnosed with epilepsy as well as the processes applied by their families. Research conducted in Kenya by Kendall-Taylor, Kathomi, Rimba, and Newton (2009) showed that if one can reduce the adverse effects on the family's wellbeing, they may be better able to cope with their child's needs.

Subsequently, the researcher formulated the following research question: What are the family processes and coping strategies of families of adolescents diagnosed with epilepsy?

1.3 Aims of the Study

The primary aim of this study was to explore the processes and coping strategies of families of adolescents diagnosed with epilepsy. A second aim was to determine quantitatively what the family process profiles, namely, family satisfaction, family functioning and family hardiness reported by the patients and family members are and to examine the differences between these profiles. Qualitatively, the researcher explored how families experience living with an adolescent diagnosed with epilepsy and what, according to the patient and family members, the impact on the family processes and functioning is. A mixed methods approach was employed to analyse the data in an attempt to answer the research question.

1.4 Significance of the Study

It is hoped that the results of this study will contribute to improved treatment and support for families with adolescents diagnosed with epilepsy. Identifying the processes and functioning of these families serves as a starting point for enhanced support for these families. The significance of the study lies in acquiring an enhanced understanding of the family processes and functioning of the families that have an adolescent diagnosed with epilepsy. It is evident from a study of the literature that the majority of previous research has focused on the experience of the patients and their parents, and not on the functioning and processes of these families.

1.5 Conceptual Framework: Family Systems Theory

Family systems theory is the conceptual framework that was employed in this study. General systems theory supports the assumption that all kinds of systems including concrete, conceptual, abstract, natural and fabricated systems have common characteristics, regardless of their internal nature (Becvar & Becvar, 2017). A system is a set of interdependent components that form an internally organized whole that operates as one in relation to its environment and to other systems (Poole, 2014). Family systems theory emerged from general systems theory, which is attributed to Von Bertanlanffy; the latter argued that organisms are complex, interactive and organized (Fleming, 2003; Von Bertanlanffy, 1972). Von Bertanlanffy introduced a broader holistic approach that examines how the components of a system interact with one another to form a whole so as to understand the dynamics involved in complex organisms (Fleming, 2003). From the perspective of family systems theory, the researcher focused on acquiring an enhanced understanding of the family's experience by studying the family unit and the specific idiosyncrasies thereof and its circumstances (Becvar & Becvar, 2014; Hauser, 1990). Through the lens of family systems theory, this study focused on family behaviour, relationships and relationship issues rather than on individual behaviour in isolation to explain why family members experience the diagnosis of epilepsy in the particular manner they do (Becvar & Becvar, 2014).

1.6 Definition of Key Concepts

1.6.1 Epilepsy

Epilepsy is a chronic neurological brain function disorder in which there are periods of altered consciousness characterized by seizures originating from abnormal electrical signals in the brain with a variety of consequences including cognitive, neurobiological, social and psychological (Carter, 2014; Espinola-Nadurille, Crail-Melendez, & Sánchez-Guzmán, 2014; Shorvon, 2016; Wang et al., 2015). The fundamental characteristic of epilepsy is recurrent and unprovoked seizures (Camfield & Camfield, 2014; Moshé, Perucca, Ryvlin, & Tomson, 2015).

1.6.2 Adolescence

Adolescence forms the developmental bridge between childhood and adulthood. It is the period in which individuals mature sexually and acquire adult responsibilities and roles; going through puberty may be regarded as a major change. For the purpose of this study, adolescents fell in the age range of 13 to 18 years. Progressing from adolescence to adulthood is one of the most challenging periods in the course of life. Furthermore, important brain changes occur that result in an imbalance and conflict between risk-taking and pleasure-seeking behaviours, and frontal executive functioning (Camfield et al., 2017).

1.6.3 Family Processes

Family processes include the processes, from the perspective of the patients and family members, of how they experience their families in terms of family satisfaction, family functioning and family hardiness. Furthermore, family processes concerns the communication, resilience, adaptation and intimacy capacity of families (Becvar & Becvar, 2014). It should be noted that at times, in this thesis, the term, complex family processes is used. In such instances, the researcher is referring to role confusion, multiple trauma and difficult situations with which the families had to deal.

- **Family satisfaction.**

For the purpose of this study, family satisfaction refers to the satisfaction of individual family members with the family as a support system, a source of emotional security and essential factors for psychosocial wellbeing. The satisfaction that family members experience seems to influence the wellbeing of a family. Happiness, which is characterized by more experiences of positive than negative affect and satisfaction with life, is derived from the overall impression that one's life is pleasant, good and satisfying to live (Lopez, Pedrotti, & Snyder, 2018). In addition, family satisfaction has an influence on various aspects of adolescent development (Braun-Lewensohn, Idan, Lindström, & Margalit, 2017).

- **Family functioning.**

Family functioning refers to the family's ability to work together as a unit to satisfy the basic needs of its members (Ryan & Keitner, 2009). Families that demonstrate effective family functioning have reported that they nurture each other emotionally, practise effective communication skills, share time and activities together, help each other, and practise appropriate parenting (Dunst, Trivette, & Deal, 1988).

- **Family hardiness.**

Family hardiness may be defined as a mediating strength between family adaptation, and stressful and challenging situations. It comprises four dimensions, namely, control, challenge, commitment and confidence (McCubbin, McCubbin, & Thompson, 1991). *Control* refers to the sense of control that a family has in relation to life events. *Challenge* alludes to a family's ability to view change as an opportunity for growth. *Commitment* refers to how active a family is orientated towards adapting to stressful life events. *Confidence* alludes to the ability of a family to find meaning in and show interest in life experiences (McCubbin et al., 1991).

1.7 Research Questions

The researcher addressed the following research questions to determine the family processes and coping strategies of families of adolescents diagnosed with epilepsy:

- **Quantitative Question**

What are the family process profiles, that is, family satisfaction, family functioning and family hardiness reported by the patients and family members? What are the differences between patients' and family members' family process profiles?

- **Qualitative Question**

How do families experience living with an adolescent diagnosed with epilepsy? What is the impact of epilepsy on the family processes and functioning according to the patients and family members?

- **Mixed Methods Research Question**

To what extent and in what ways do the quantitative data from adolescent epilepsy patients and family members concur with the qualitative results?

1.8 Research Design and Methodology

The researcher used a mixed methods approach; both quantitative and qualitative data were collected consecutively. Quantitative data were collected by means of a compiled questionnaire that comprised a biographical questionnaire and the following standardized scales, which all the participating family members completed: Family Satisfaction Scale (FSS) (Olson & Wilson, 1982); Family Functioning Scale (FFS) (Dunst et al., 1988); Family Hardiness Index (FHI) (McCubbin et al., 1991); and the Family Assessment Device (FAD) (Epstein, Baldwin, & Bishop, 1983). The qualitative data were collected through semi-structured interviews and Graphic Family Sculpting (GFS) (Venter, 1993).

Purposive sampling was employed. It included adolescents aged 13-18 years who had been diagnosed with epilepsy and to whom their treating neurologists had suggested they participate. Quantitative and qualitative data were treated as equally important. The researcher employed a mixed methods design so as to acquire an enhanced understanding of the family process profiles and experience of the families living with an adolescent diagnosed with epilepsy. The family processes and functioning of these families related to family satisfaction, family functioning and family hardiness. Comparisons were made between family and patient process profiles and experiences. The analysis involved the divergence and convergence of quantitative and qualitative results.

1.9 Division of Chapters and Layout of the Thesis

- **Chapter 1: Introduction**

In this chapter, the introduction comprises the background of the study, statement of the research problem, purpose and significance of the study, definition of terms, research questions, limitations, delimitations and overview of the research design.

- **Chapter 2: Literature Review**

In this chapter, the literature on epilepsy, adolescence, family processes, psychological implications, psychosocial issues, emotional issues and family processes in conjunction with adolescence and the experience of epilepsy is reviewed. The literature sheds light on whether further research on family processes could contribute to the existing knowledge on the effect on the family if there is an adolescent diagnosed with epilepsy in the family.

- **Chapter 3: Theoretical Framework and Paradigmatic Point of Departure**

In this chapter, the theoretical approach and the paradigmatic point of departure employed in the study are described. The researcher used family systems theory from a position of critical realism so as to understand and conceptualize the impact of the epilepsy of the adolescent on the family.

- **Chapter 4: Research Methodology**

In this chapter, the research methodology that was employed and the procedures that were followed to ensure the study was conducted ethically with high validity, are described. The researcher focused on the quality of research in this study by considering its trustworthiness.

- **Chapter 5: Findings**

In this chapter, the research process and participants' demographic information are presented. The results of the quantitative and qualitative data analysis are detailed.

- **Chapter 6: Discussion**

The integration and discussion of the findings, implications of the findings for theory and practice, conclusions in the context of relevant literature, recommendations for further research and conclusions are discussed in Chapter 6. Furthermore, recommendations in relation to possible intervention strategies to optimize affected adolescents and their families are explained. In addition, shortcomings of the design and other limitations are noted.

1.10 Conclusion

The primary aim of this study was to explore family processes from the perspective of adolescent patients with epilepsy and their family members. A secondary aim was to describe family processes in terms of satisfaction, family functioning, and family hardiness. In Chapter 1, the research process was introduced and the chapters that follow were outlined. In Chapter 2, the literature of the subject matter that relates to this study is reviewed.

CHAPTER 2: LITERATURE REVIEW

The focus of the literature review is on the impact of epilepsy on family processes and functioning in families with an adolescent diagnosed with epilepsy. A literature map depicts the extent of the literature review. The experience of the family as a whole, the patient, and the experience of the family members are explored so as to examine the psychological effects of epilepsy. It appears that families face many emotional challenges with a diagnosis of epilepsy. Literature on adolescence, family processes, the psychological implications thereof, psychosocial issues and family processes associated with adolescence, and the experience of epilepsy are reviewed.

2.1 Literature Map of the Review

In Figure 2.1, a literature map, which represents a visual picture of the existing research of relevant topics, is depicted (Creswell, 2014).

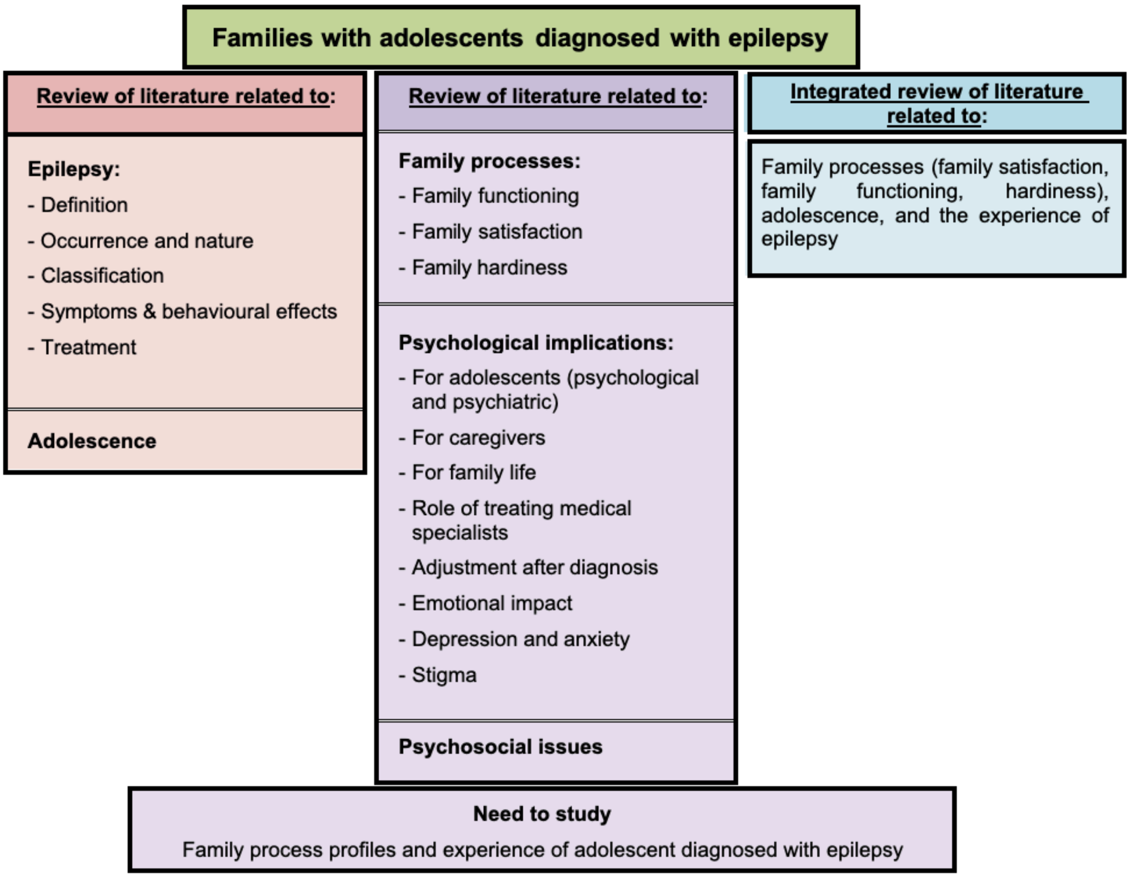


Figure 2.1: Literature of existing research on relevant topics for this study

2.2 Epilepsy and Adolescence

Different aspects related to epilepsy including the definition, occurrence and nature, classification, symptoms and behavioural effects, and treatment of epilepsy is subsequently discussed.

2.2.1 Epilepsy

Epilepsy is a chronic neurological brain function disorder in which there are periods of altered consciousness characterized by seizures originating from abnormal electrical signals in the brain with cognitive, neurobiological, social and psychological consequences (Carter, 2014; Espinola-Nadurille et al., 2014; Shorvon, 2016; Wang et al., 2015). The fundamental characteristic of epilepsy is recurrent and unprovoked seizures. Furthermore, the location of the origin of the seizure in the brain as well as the pattern of seizure activity through the brain influences the symptoms present during the seizure (Camfield & Camfield, 2014; Engel, 2013; Moshé et al., 2015).

2.2.1.1 Occurrence and nature.

Epilepsy affects an estimated 65 million people worldwide. It is the most common chronic serious brain disorder and neurological disease in the general population, and affects people of all ages, races, social classes and countries (Engel, 2013; Moshé et al., 2015). Furthermore, it is the most common serious childhood neurological condition and is associated with seizure-related injuries, increased mortality and severe psychological outcomes. Epilepsy affects half a million children in the United States and further affects their quality of life (Chong et al., 2016; Faruki, 2013). According to Wang et al. (2015), nearly 80% of epilepsy occurs in developing countries. In support, a systematic review of selected literature conducted by Camfield and Camfield (2015) found the prevalence and incidence of epilepsy in children appears to be lower in developed countries whereas the highest incidence is found in rural areas of underdeveloped countries. Epilepsy has important implications for the development and emotional health of children, parents, family members and society. Moreover, it is a pervasive disorder that can change over time (Khan et al, 2013; Tolaymat, Nayak, Geyer, Geyer, & Carney, 2015). The changes can include social, academic and behavioural difficulties and challenges.

Epilepsy is a unique and complex condition compared to other chronic illnesses. The unpredictability of when and where the next seizure might occur seems to make people with epilepsy live in constant fear of the unknown. Epilepsy is a major burden with regard to seizure-related comorbidities, disability, stigma, mortality and financial implications. The uniqueness of each sufferer’s epilepsy is noteworthy (Solomon & McHale, 2012). Treatment and emotional issues are dependent on the type and frequency of seizures and the specific impact on the child’s life (Tolaymat et al., 2015). The treatment mostly applied is medication, which does not address the accompanying problems that might have a deleterious effect on a child’s quality of life (Solom0on & McHale, 2012). Carter (2014) noted that although genetic factors may play a role in the cause of some cases of epilepsy, people can experience epilepsy because of a head injury, brain tumour, stroke, alcohol and/or drug abuse, an infection such as encephalitis and meningitis, and trauma at birth; however, the cause is often unclear.

2.2.1.2 Classification.

There are two main categories of types of seizures, namely, generalized and partial seizures (Carter, 2014; Engel, 2013). The various seizure types within these broad groupings vary and depend on precisely where in the brain the epileptic activity starts and how far it spreads. Seizures may vary from brief episodes of lapses of attention to long severe convulsions (Engel, 2013; Shorvon, 2016).

Generalized tonic-clonic seizures are associated with the classic symptoms of loss of consciousness, tongue biting and generalized tonic-clonic movements of the limbs and incontinence. Examples include tonic-clonic, tonic, atonic, myoclonic- and absence seizures (Engel, 2013). Both hemispheres of the brain are initially involved in a seizure. Furthermore, the whole brain is affected by the changed electrical activity and the period of recovery ranges from a few minutes to a few hours (Engel, 2013; Shorvon, 2016; Solomon & McHale, 2012).

Partial seizures occur where epileptic activity begins in one hemisphere of the brain. The seizures may be classified as *simple,* that is without changes in consciousness and *complex,* which is associated with a change in consciousness (Engel, 2013; Shorvon, 2016). More than half of patients with partial seizures have complex partial seizures, which are also called temporal lobe epilepsy (Engel, 2013; Solomon & McHale, 2012). With temporal lobe epilepsy, electrical activity could also occur in other lobes, causing frontal, parietal and occipital lobe epilepsy (Solomon & McHale, 2012).

2.2.1.3 Symptoms and behavioural effects.

Symptoms may be divided into *pre-ictal* symptoms and *ictal* symptoms. The former is present before the seizure and the latter, during the seizure (Carter, 2014). Some individuals experience warning signs, pre-ictal symptoms or auras before having a seizure (Carter, 2014). In complex partial epilepsy, these signs include autonomic sensations such as stomach fullness, blushing and respiration changes; affective states like depression, panic and fear; cognitive sensations including dreamy states, forced thinking and *déjà vu*; and automatisms such as rubbing, chewing and lip smacking (Carter, 2014).

Ictal symptoms include short, disorganized, uninhibited behaviour, memory loss during the seizure and resolving delirium after the seizure (Sadock & Sadock, 2007). The most frequently reported psychiatric abnormalities in patients with epilepsy are personality disorders, which are most likely to occur in patients with temporal lobe epilepsy (Sadock & Sadock, 2007). These are known as inter-ictal symptoms. Some patients experience psychotic symptoms, episodic violence and mood disorder symptoms (Engel, 2013). Of all epileptic patients, 30-50% experience psychiatric problems sometime during the course of their illness. Moreover, most people with epilepsy experience a change in personality as a behavioural symptom (Sadock & Sadock, 2007).

Status epilepticus occurs when a prolonged epileptic seizure or series of repeated seizures occur one after the other without regaining consciousness between seizures (Carter, 2014). This is a medical emergency and can result in long-term disability or death if not treated promptly (Walker & Hirsch, 2016). The most common cause of status epilepticus is when patients neglect to take their anti-epileptic medication (Carter, 2014; Perucca, 2016).Patients with epilepsy find that specific factors can trigger a seizure such as lack of sleep, fever, stress, use of certain drugs, fatigue and exposure to flashing lights (Carter, 2014; Chong et al., 2016).

2.2.1.4 Treatment.

Although treatment goals are focused on the physical complications of epilepsy through seizure control, patients face other challenges as well, for example, social complications like unemployment, driving restrictions and social anxiety as well as psychological challenges such as anxiety, depression and low self-esteem (Wang et al., 2015). Different antiepileptic medications are available for various types of seizures and usage can cause some degree of cognitive impairment (Chong et al., 2016; Engel, 2013; Perucca, 2016). Making the correct diagnosis allows treating medical practitioners to recommend appropriate therapy. Most children with epilepsy respond positively to antiepileptic medications. However, adolescents may experience difficulty complying with treatment (Nabbout, Andrade et al., 2017). It is important to identify the effectivity of the medication early in the treatment process so as to optimize neurodevelopment (Tolaymat et al., 2015). Camfield and Camfield (2014) who conducted population-based studies found that approximately 50-60% of children with epilepsy will eventually be seizure and medication free. If a child with epilepsy experiences numerous treatment failures, uncertainty regarding the attainment of remission will ensue (Chong et al., 2016).

Psychotherapy, family therapy and group therapy can assist when addressing psychosocial issues linked to epilepsy (Appleton & Gibbs, 2014). Geerlings et al. (2016) in a study in a tertiary referral centre in The Netherlands found that it is important to include the services of a psychologist, educationalist and social worker as part of epilepsy treatment.

A study conducted in Saudi Arabia on 116 patients with idiopathic epilepsy found aspects that significantly affect a patient's adherence to prescribed medication (Gabr & Shams, 2015) including the number of family members, mother's age, number of antiepileptic medications that the patient uses, family support, stability of the parent's marriage, interval and occurrence of seizures, and frequency of consultations with healthcare practitioners and the nature of this relationship (Gabr & Shams, 2015). The researchers found that forgetfulness and the fear of possible side-effects of the medication were the most common reasons for non-adherence. More patients in the non-adherent group felt stigmatized in comparison with patients with a strong sense of normality.

The transition to adult medical care for adolescents with epilepsy creates a challenge on its own. Geerlings, Aldenkamp, De With et al. (2015) found that the risk of psychosocial problems should receive more attention so as to assist in this transition and possible future challenges.

Thus, it is evident from existing research that the diagnosis of epilepsy has particular practical, physical and emotional challenges. In the next section, literature on adolescence is reviewed. Furthermore, links with epilepsy during adolescence are outlined.

2.2.2 Adolescence and Chronic Illness

Adolescence forms the developmental bridge and represents the transition between one's childhood years and becoming an adult. In this phase, adolescents go through puberty, mature sexually, and acquire adult roles and responsibilities (Camfield et al., 2017). For the purpose of this study, adolescents are regarded as those from 13 to 18 years of age (Atwater, 1983; Papalia, Martorell, & Feldman, 2014). The transition from adolescence to adulthood is one of the most challenging periods of life and is characterized by important brain changes that create conflict between risk-taking and pleasure-seeking behaviours, and the frontal executive function (Camfield et al., 2017; Preto, 2011). Cognitive development may be classified into three stages: A beginning stage, 10 to 13 years of age that is associated with concrete thinking; a middle stage, 14 to 17 years of age that is characterized by abstract introspective and analytical thinking; and the last stage, 18 to 21 years of age that is associated with the start of adult reasoning (Camfield et al., 2017).

During the early adolescence years, children experience rapid and intense physical bodily development and mature sexually; in addition, they are very aware of these changes (Cohen et al., 2013). It is not always easy for young adolescents to accept their changed physical appearance (Cohen et al., 2013). The age at which adolescents reach physical maturity seems to influence their psychological development, especially when they mature earlier or later than the norm. Emotional development includes important changes in relation to the primary task of personality and identity development and formation, self-understanding, and experiencing and dealing with emotions (Cohen et al., 2013; Wood, 1996). Important aspects of social development include the parent-adolescent relationship, relationships with peers and moral development (Cohen et al., 2013). During adolescence, being moody, exhibiting high-risk behaviour and conflict with parents and authority figures may occur (Cohen et al., 2013). Adolescents' age and level of development may influence their perception and understanding of trauma, exposure to risk, susceptibility to parental distress, coping styles, self-concept, adaptation and social skills (Goldenberg & Goldenberg, 2013). Adolescents tend to challenge rules, renegotiate roles and move more toward their peer culture for guidance and support (Cohen et al., 2013). Adolescents must form their own identity and begin to establish autonomy from their family (Goldenberg & Goldenberg, 2013).

Adolescents form a new balance of autonomy and belonging in the family with increased independence and firmer boundaries (Cohen et al., 2013). It is difficult for families to negotiate with chronically ill adolescents (Wood, 1996). Families of chronically ill adolescents might wonder if their adolescents will be able to manage their illness on their own because these families generally have diffuse boundaries (Wood, 1996). Parent-adolescent struggles in relation to the illness form part of dysfunctional patterns in the family or serve as an indication of emotional challenges within the family (Wood, 1996). Identity formation is a primary task during adolescence; this becomes a crucial and challenging stage for chronically ill children (Wood, 1996). Adolescents need to develop firm boundaries between their self-identity and the illness, and not think of themselves or get referred to as epileptics, but rather as people who *have* epilepsy (Wood, 1996). A study that employed a family systems approach on coping with cancer found that cancer-generated family stress, traumatic memories and fears created a crisis as well as an opportunity by providing a motivational stimulus for families to bond, support and relate as they had not done previously (Doumit & Khoury, 2017; Wellisch, 1996). It is clear that adolescent years encompass many other emotional and physical challenges. However, a diagnosis of epilepsy results in extra challenges with which to deal. A review of the literature on family processes and the psychological implications and psychosocial issues thereof follows.

2.2.3 Family Processes

The role of the family appears to be crucial in adolescent development. Furthermore, the family is a support system to which adolescents can turn when they have fears, uncertainties and doubts about themselves and their future (Caprara, Pastorelli, Regalia, Scabini, & Bandura, 2005). The family serves as a preparation centre for the adolescent's entrance into the world of adult chores, responsibilities and commitments (Goldenberg & Goldenberg, 2013). The family metamorphosis involves profound shifts in relationship patterns across different generations. Some of the challenges that adolescents and families experience are on socio-cultural, physical and emotional levels and also include changes in the family structure (Becvar & Becvar, 2017). Family processes are discussed by examining family functioning, family satisfaction and family hardiness as well as family processes and functioning in conjunction with chronic illness.

In the chronic phase, after receiving the diagnosis, families attempt to adapt and cope with treatment courses, and sometimes feel that the treatment is failing them and might feel isolated from support structures. When looking at processes, emphasis must be placed on *how* families do best what it is *they* want to do rather than emphasizing *what* they are doing (Becvar & Becvar, 2014). In addition, Becvar and Becvar (2014) viewed health as the family's success in their functioning to reach their own goals, practising effective communication, expressing a wide variety of emotions, having a transcendental value system, and sharing rituals and traditions.

2.2.3.1 Family functioning.

It is evident that the family plays an essential role in the wellbeing of its members. Healthy functioning families are better equipped to cope with challenging experiences and deal with unexpected situations (Dunst et al., 1988; Shek, 1998). Families with effective family functioning nurture one another emotionally, practise effective communication, spend time with one another, support one another and practise appropriate parenting skills (Dunst et al., 1988) Families with healthy functional processes may cope better with the challenges of adolescence and the added challenge of the diagnosis of epilepsy. Characteristics of healthy, functional family processes include clear and congruent communication, the ability to adapt to situations (resilience) and have a capacity for intimacy (Becvar, 2007; Becvar & Becvar, 2014; Masten & Reed, 2005). The McMaster model of family functioning proposes six features of healthy and well-functioning families: The ability to solve problems; the capacity to communicate effectively; appropriate role allocation; affective responsiveness; empathetic affective involvement; and the application of flexible behaviour control (Epstein, Ryan, Bishop, Miller, & Keitner, 2003).

Stuart and Jose (2012) found significant discrepancies between adolescents and parents' perceptions of family functioning for all positive family dynamics, but not for family conflict. According to Spangenberg and Lalkhen (2006), parents feel less stressed and experience less of a burden if they feel they are able to handle their child's illness with the necessary skills to deal effectively with seizures. They also found that the burden of care might fall more heavily on one family member, that there is strain on the sibling sub-system, and parents often experience feelings of helplessness and fear; furthermore, these can all result in overindulgence and/or overprotection of the child (Spangenberg & Lalkhen, 2006).

Mu (2008) noted that family functioning is an important theme to examine during the health-illness transition and parents tend to suffer in silence. The family's response to illness plays an important role in coping; some families may develop a family identity that becomes confused with the illness entity (Rodenburg, Wagner, Austin, Kerr, & Dunn, 2011; Wood, 1996). These families might develop maladaptive patterns of functioning that may, in turn, influence the disease process. Because a cross-sectional design has been employed in most studies, there is not a clear understanding of the history of the processes that families use to manage childhood epilepsy in a successful way and therefore, further studies are imperative (Rodenburg et al., 2011).

2.2.3.2 Family satisfaction.

Family satisfaction influences the wellbeing of a family and affects various aspects of adolescent development including individuation and differentiation (Braun-Lewensohn et al., 2017). Koen (2012), who conducted research on family psychosocial wellbeing in a South African context by using a mixed methods approach, found that family satisfaction correlates with the quality of the parent-adolescent relationship, positive adjustment, successful growth, successful development and self-esteem in the family and adolescents. Dissatisfaction with family life and processes may cause emotional conflict and turmoil during adolescence. Research on families who had to deal with cancer found that these families prefer to share responsibility in decision-making, need information about the cancer they face, and want to be involved in decision-making; the latter is one of the most important factors in family satisfaction with medical treatment (Doumit & Khoury, 2017; Wellisch, 1996). If adolescents are satisfied with how they experience their family, it may have a positive effect on the challenges they generally encounter.

2.2.3.3 Family hardiness.

Family hardiness may determine how families approach difficulties in their lives. In a Taiwanese study on factors of caregiver burden and family functioning among family caregivers living with schizophrenia, Hsiao and Tsai (2015) highlighted the importance of a sense of coherence and family hardiness in adaption processes for individuals and family members. Perceived social support and parent self-efficacy influence family hardiness and how the perception of hardiness is associated with less distress. Weiss et al. (2013) confirmed this in their study on family hardiness, social support and self-efficacy in mothers of children with autism spectrum disorders.

2.2.3.4 Family processes, chronic illness, and epilepsy.

In this section, family processes, chronic illness and epilepsy in general with a focus on family functioning, satisfaction and hardiness are further discussed.The familial background and environment is essential and predictive for the coping, psychological wellbeing and development of an adolescent with a chronic illness such as epilepsy (Smith et al., 2014). It is imperative that the progression of the epilepsy and parental burden be included in a comprehensive treatment approach. The burden of care might fall more heavily on one member, could lead to resentment and increased family tension, and result in putting plans on hold for the future (Dehn, Korn-Merker, Pfäfflin, Ravens-Sieberer, & May, 2014; Ryu et al., 2015). The family might spend less time enjoying activities outside the home, fearing that the adolescent might have a seizure, and also stop inviting friends home. This has a crucial impact on the normal emotional development of adolescents because friends, socializing and their peer group play an important role during adolescence (Ryu et al., 2015).

Adolescent epilepsy affects the entire family, resulting in a challenging time with higher levels of anxiety and stress because of increased pressure for change and the use of family resources (Appleton & Gibbs, 2014; Khan et al., 2013). Stress may be especially high at the onset of epilepsy. Parents who have observed their child’s first seizure have reported that they feared that their child was dying, which led to higher stress levels and disruption within the family (Appleton & Gibbs, 2014; Khan et al., 2013) Smith et al. (2014) revealed that cognitive deficits and learning problems are additional stressors for the family. To live with an unpredictable and episodic illness such as epilepsy is more disruptive for families than living with illnesses that are more predictable and stable. Family stress has the potential to affect parents’ confidence and behaviour (Smith et al., 2014). Parents of children with chronic conditions experience stress in their marital roles, and frustration and conflict in relation to childrearing issues (Appleton & Gibbs, 2014). Many families lack knowledge about the management of epilepsy, which may cause stress (Al-Khateeb & Al-Khateeb, 2014). Families of children with epilepsy have more parenting and relationship difficulties and need to adjust to a more disrupted environment than families of children with other chronic conditions. A chronic illness with unpredictable characteristics like epilepsy might put a family at risk for poor communication, cohesiveness, integration and self-image dilemmas (Appleton & Gibbs, 2014). A family with an epileptic child tends to conceal that their child has epilepsy (Ryu et al., 2015). These families choose self-regulation to re-organize the roles and rules within the family so as to create consistent coping patterns (Appleton & Gibbs, 2014).

The psychosocial impact of epilepsy on the child and family's daily life depends on several aspects and plays a role in the real or perceived adjustment to the illness (Camfield et al., 2017). The severity of epilepsy, complexity of the clinical management, and meaning of the illness to the child, family and society all influence the adjustment to the situation. These can include restrictions in the daily routine of the child and family, their coping abilities, levels of social support, and the extent of resources available to deal with the diagnosis (Rood, Schultz, Rausch, & Modi, 2014). A tiny proportion of children with epilepsy may die unexpectedly because of their epilepsy or seizures (Camfield & Camfield, 2014).

Having a child with epilepsy results in many expenses because consultations with specialists, medication and special medical tests are costly. Furthermore, if a parent stops work to take care of the patient, this will result in reduced income for the family and possibly fewer activities for enjoyment (Spangenberg & Lalkhen, 2006).

Spangenberg and Lalkhen (2006) demonstrated that siblings in families with an epileptic child experience more psychiatric challenges than siblings in a control group. Parents of a child with a chronic illness often neglect their other healthy children and sometimes siblings struggle to adapt and may experience a higher level of sibling rivalry. Siblings may face many disappointments and miss out on school activities because activities involving the epileptic child may have been terminated (Spangenberg & Lalkhen, 2006).

When looking at other chronic illness characteristics and looking at, for example, diabetes, it is evident that certain aspects of diabetes also have a strong impact on the family (Brody & Sigel, 1990). Dietary control, as a basic part of diabetes management, disrupts family meals, which may be a primary family ritual. The practice of the administration of insulin by injection will first be done by a parent and subsequently, the adolescent patient should self-inject. The involvement of a parent in the affairs of their adolescent's body can create an uncomfortable situation. Brody and Sigel suggested that the onset and continued presence of diabetes, in conjunction with other family processes, may ‘transmit’ the effects of illness onto the adolescent’s development. Brody and Sigel examined whether the illness influences how parents interact or talk with each other and the patient to determine whether this has an effect on how patients experience their diabetes. They found that the ego development of adolescents was important for compliance, healthy behaviour, judgements of risk, and adjustment to the immediate and long-term situation. Brody and Sigel studied the relationships between the family’s functioning as a whole and the child’s adjustment. The monitoring of an adolescent diagnosed with epilepsy and being aware of all their actions disrupt the normal independence that an adolescent is meant to develop.

Chronic childhood illnesses affect the entire family system. Becoming comfortable with the diagnosis of epilepsy starts by processing the emotions experienced directly after the diagnosis (Cousino & Hazen, 2013; Pembroke, Higgins, Pender, & Elliott, 2017). Early after the diagnosis, the families’ experience may include immediate individual emotional and psychological reactions, parents’ coping patterns and a reorganization of the functioning of the family. Children with a new diagnosis of epilepsy and their families, especially those with co-morbid conditions, are at risk of reduced quality of life at the time of diagnosis and thereafter and should be evaluated to identify possible psychosocial problems so as to apply early intervention if necessary (Ferro, Camfield et al., 2013).

Lim and Ashing-Giwa (2013), in a study that focused on family functioning and communication associated with the health-related quality of life of Chinese- and Korean-American breast cancer survivors, found that communication within families has an impact on their health-related quality of life. Botha and Booysen (2014) revealed that South Africans who live in balanced functioning families are more satisfied with life and happier compared with those who live in extremely or mildly dysfunctional families. The processes in and functioning of families are unique in the context of a chronic illness. Crespo et al. (2013) found that a chronic illness in a family member affected the type and regularity of family’s rituals and routines. They also found that whole-family interactions performed important functions for families and patients, created resources in the management of the chronic illness, ensured emotional support and provided the family with a sense of normality. Crespo et al. (2013) concluded that family rituals and routines played a role in positive adjustment and health outcomes for family members and patients. Hsiao (2014) in a study conducted on 155 Taiwanese parents from 83 families with children with Down syndrome found that those families that had older children with Down syndrome that a higher family income, fewer family demands and a larger involvement of social support experienced healthier functioning. It seems as though social support can mediate the effects of family demands on family functioning. Care of children with Down syndrome and their families may be more effective if health care practitioners working with these families are aware of factors that contribute to healthy family functioning (Hsiao, 2014).

Widespread misconceptions about epilepsy exist. A study done in Mali on beliefs and attitudes in relation to epilepsy suggested that education initiatives must focus on the entire population, including traditional healers, to provide knowledge, improve the quality of life for people living with epilepsy and reduce the stigma attached to it (Maiga et al., 2014).

In a study on family communication in the context of paediatric epilepsy, O'Toole et al. (2015) found that children with epilepsy experienced the following parental barriers: a desire to keep epilepsy a secret, overprotection, a tendency to deny that the child has epilepsy and the imposition of greater restrictions than on siblings with no diagnosis of epilepsy. Effective communication-focused interventions can assist by discussing epilepsy within the home.

Parents of older children and children with negative coping strategies reported lower family hardiness in a study that assessed aspects related to family hardiness in families of children who have to cope with medical procedures related to a chronic illness (Woodson, Thakkar, Burbage, Kichler, & Nabors, 2015). Negative child coping may result in negative effects on the family and treating health practitioners should provide ideas for positive child coping. A national survey done in South Korea with self-report questionnaires on the effects on the needs and family hardiness of caregivers of cancer patients found that family hardiness was a significant predictor of positive family processes (Jeong et al., 2016). Walsh (2015) revealed that family resilience helps family members to cope with stress, and maintain family functioning and integrity (Walsh, 2015). Family resilience and coping ability improves when family members receive emotional support from their extended family, they have economic stability and receive information about epilepsy (Benson et al, 2016).

It appears as though family processes differ from family to family and undergo challenges when a diagnosis of epilepsy is made during adolescent years. Families with a child with epilepsy generally suffer with a range of family factors including problems with family functioning and lower parent-child relationship quality.

2.2.4 Psychological Implications

Epilepsy has several psychological implications and affects a variety of parties involved.

2.2.4.1 Psychological and psychiatric effects of epilepsy on adolescents.

Epilepsy affects the quality of life of adolescents who have been diagnosed with the illness. Adolescents who have the illness are four times more likely to have a higher occurrence of psychological and psychiatric difficulties than those in the general population (Appleton & Gibbs, 2014; Faruki, 2013). Research conducted in Iran found that the quality of life of adolescents with epilepsy was low. Furthermore, suggestions on how to improve the psychological status of patients and to reduce their risk factors for a compromised quality of life were made (Cianchetti et al., 2015; Zamani, Shiva, Mohammadi, Gharaie, & Rezaei, 2014).

Six themes emerged from a qualitative study that focused on children's experience of epilepsy, and involved 43 articles and 951 participants aged 3 to 21 years across 21 countries: Loss of bodily control, loss of privacy, inescapable discrimination and inferiority, therapeutic burden and futility, navigating health care, and recontextualizing to regain normality (Chong et al., 2016). Population-based studies conducted by Engel (2013) and Reilly, Kent and Neville (2013) found high rates of psychopathology in children with epilepsy and recommended these children be monitored for the presence of behavioural difficulties. Research has also revealed that children with epilepsy are at higher risk for psychiatric and behavioural disorders such as depressive and anxiety disorders, attention deficit and/or hyperactivity disorder, autism spectrum disorder, low self-esteem and social withdrawal, and recommended that further studies on how these children and their families can have better quality of life be conducted (Chong et al., 2016; Räty & Wilde-Larsson, 2011; Reilly et al., 2013). Mishra, Upadhyay, Prasad, Upadhyay, and Piplani, (2017) found that in India the age of onset of epilepsy, duration of illness and frequency of seizures, and an increase in these factors, were significantly correlated with behavioural problems. According to Camfield et al. (2017), children with epilepsy may have their first sexual encounter early. Furthermore, these children may experience unsatisfactory long-term sexual experiences and possible behavioural problems later in life.

Faruki (2013), in a cross-sectional study conducted in Bangladesh on 50 epileptic children aged 5 to 17 years, found that emotional disorders occur more often than behavioural disorders among these children. Furthermore, childhood epilepsy can cause problems for some children in the following areas: Behavioural and emotional adjustment, social competence, psychological and psychiatric difficulties, and academic achievement. As a result of abnormal brain function or formation, some of these challenges may occur even when antiepileptic medication controls seizures well (Faruki, 2013). Many adolescents experience epilepsy as a self-limiting illness and perceive it has a larger negative social impact then other chronic illnesses. Adult patients with epilepsy are more likely to be unemployed, complete only six or fewer years of school, be socially isolated, be financially dependent and are less likely to get married in comparison to a matched control sample (Appleton & Gibbs, 2014; Engel, 2013). The transition from paediatric to adult health care for adolescents with epilepsy is challenging for the family, patient and health care practitioners (Camfield et al., 2017; Camfield, Breau & Camfield, 2001). The literature also indicates that adolescents with epilepsy are significantly more at risk for challenges in effective communication and emotional disorders (Camfield et al., 2017).

2.2.4.2 Psychological effects of epilepsy on caregivers and family members.

Caregivers play a significant role in helping the child with epilepsy adapt to the illness. Their functions include seeking treatment, ensuring the child complies with the treatment, facilitating the child’s functioning at and away from home, and managing the impact of other people’s reactions and attitudes to the child. A cross-sectional study that included 213 consecutive parents who accompanied their children diagnosed with epilepsy at regular checkups at the Child and Adolescent Neurology and Psychiatry Clinic in Belgrade, Serbia, found that parents want their family and friends to know that their child has epilepsy as this serves as support in coping (Gazibara, Nikolovski, Lakic, Pekmezovic, & Kisic-Tepavcevic, 2014). These parents felt the most confident when taking care of their child during seizures and least confident when their child went on school outings that lasted a few days. A higher parental education level served as an independent predictor of higher epilepsy knowledge in this study. Gazibara et al. and McEwan et al. (2007) recommended improved knowledge and education on epilepsy-related issues for patients, families, schools and communities.

Caring for those with epilepsy is emotionally demanding. Caregivers carry a burden and have a greater tendency to feel depressed (Karakis et al., 2014). A qualitative study conducted in Sri Lanka found that parents with children with epilepsy were concerned about the education, safety, marital prospects, employment, unpredictability of seizures and unawareness of the influence of stigma associated with epilepsy (Murugupillai, Wanigasinghe, Muniyandi, & Arambepola, 2016). A lack of effective parental coping strategies may cause parenting stress and less effective parenting behaviour as well as a negative effect on the interrelationships between the child and parent. Jones and Reilly (2016) found that a higher level of parental anxiety, which is common among parents of children with epilepsy, may be indicative of a lower quality of life for these children.

It is one of the most anxiety-provoking experiences for a parent to witness a seizure in their child. Parents fear exposing their child to friends or family members because of a sense of shame and rejection as they tend to blame themselves and withdraw from social activities (Rodenburg et al., 2013). Educating families about epilepsy is important as the primary caregiver's perception of epilepsy has the strongest impact on the stigma that an adolescent with epilepsy may experience (Ryu et al., 2015). Rodenburg et al. (2013), in a study on parents of 73 children with epilepsy found that controlling parents imposed more restrictions on their children. Consequently, parents tend to isolate themselves and risk losing social support while grieving the loss of their 'normal' child. This can have an effect on family processes. Research has shown that these parents often experience feelings of helplessness and fear, and tend to overprotect or overindulge the child (Rodenburg et al., 2013).

Geerlings, Aldenkamp, Gottmer-Welschen et al. (2015) found that risk factors for maladaptive development included chronic refractory epilepsy, low intelligence and poor family support. Geerlings, Aldenkamp, Gottmer-Welschen et al. (2015) suggested that the early discovery of patients at risk could lead to preventative measures and emphasized the importance of a multidisciplinary approach during transition. In a 10-year follow-up study conducted by Jonsson, Jonsson, and Eeg-Olofsson (2014) on psychological and social outcomes in well-functioning Swedish children and adolescents with childhood-onset epilepsy identified social, behavioural and emotional problems. Jonsson et al. suggested that the early provision of information can increase knowledge about epilepsy and associated psychological co-morbidities, and decrease the risk for depression, social anxiety and low self-esteem.

2.2.4.3 Depression and anxiety.

Anxiety and depression, which occur in children with epilepsy and their parents, do not always receive attention and treatment even though effective treatments are available (Jones & Reilly, 2016; Nabbout, Andrade et al., 2017; Nabbout, Camfield et al., 2017). A study conducted in Brazil linked low scores of anxiety with infrequent seizures, and high scores of anxiety and depression with the occurrence of seizures in public places (Siqueira, Oliveira, Siqueira, & De Souza, 2015). A major concern regarding the long-term adjustment to a chronic illness is depression, even though not all people with a chronic illness are diagnosed with depression (Baldin, Hesdorffer, Caplan, & Berg, 2015; Schraegle & Titus, 2017). Research has demonstrated depression and not aspects of seizures or the quality of life predicts suicidal tendencies in people with epilepsy (Hecimovic et al., 2012). Puka, Widjaja, and Smith (2017) found that caregiver anxiety, depression and unemployment play a major role in patient anxiety and/or depression. Research on a community-based sample found that there is no significant association between childhood epilepsy, psychiatric disorders and suicidal behaviour (Baldin et al., 2015). Puka et al. found that adolescent girls experienced more anxiety symptoms than adolescent boys and there was a negative association between depression and the duration of epilepsy in children. Research has also revealed increased levels of anxiety and depression, decreased cognitive function, sexual dysfunction, various behavioural problems and unemployment among persons diagnosed with epilepsy (Al-Khateeb & Al-Khateeb, 2014). A study conducted in Sarajevo on male and female patients aged 18 years and older revealed that the level of unemployment and hopelessness has a predictive value for suicidal ideation in epilepsy patients (Loga Andrijić, Alajbegović, Loga Zec, & Loga, 2014). Consequently, it is of importance to explore how earlier processes, while patients are adolescents, can aid in working towards a better outcome for adult patients with epilepsy.

2.2.4.4 The role of the treating medical specialists.

In South Africa, the lack of resources in health care systems affects epilepsy treatment; the outcomes are not as effective as they could be particularly in relation to treatment compliance and appropriate treatment (Williams, Nefdt, & Wilmshurst, 2015). Veeravigrom, French, Thomas, and Sivaswamy (2013) conducted a retrospective study in Michigan in Detroit to determine compliance with the American Academy of Neurology quality measures for epilepsy care in a paediatric epilepsy clinic; results revealed that practitioner education, application of an automated tracking system and electronic checklists may improve compliance and patient care. Physicians are the leading sources of information of epilepsy, but do not employ effective behavioural and psychological methods sufficiently (Kolahi et al., 2017). Reasons for noncompliance in epilepsy include a lack of clear instructions, misinterpretation of instructions and a lack of proper counselling in relation to safety issues (Veeravigrom et al., 2013). Treating medical specialists’ knowledge and attitudes towards illness influence the quality of patient care. Elliot and Shneker (2008) noted that patients without a diagnosis of epilepsy forget 50% of what they were told in a medical consultation after five minutes. In addition, only 20% of patients can recall such information and there is a 50% improvement in retention when patients receive additional information leaflets. It is imperative that health care practitioners tailor information to the adolescent and family’s circumstances, needs and stage of emotional adjustment to the diagnosis of epilepsy considering information seeking may serve as an element of constructive adjustment in persons with epilepsy (Elliot & Shneker, 2008). To ask patients open-ended questions about their concerns regarding epilepsy may be a simple but effective ‘needs assessment’ to assist treating healthcare practitioners to provide purposeful and specific education.

Arestedt, Persson, and Benzein (2014) in a study on nurses in Scandinavia found that a family systems nursing approach may improve the management of situations with family members and strengthen the family's resources. Healthcare practitioners are encouraged to focus on patients and their families, provide guidance on how to access community resources and work with caregivers to improve epilepsy self-management skills (Shorvon, Perucca, & Engel, 2015; Smith et al., 2014). Healthcare practitioners play an important role in the adjustment, coping and managing of the adolescent with a diagnosis of epilepsy as well as their compliance with treatment.

2.2.4.5 Adjustment after diagnosis.

Families face specific challenges after receiving the diagnosis of epilepsy and need time to adjust as well as skills (Pembroke et al., 2017). Kerne and Chapieski (2015) identified the following risk factors for poor adaptive functioning: the use of more anti-epileptic medication, a longer duration of seizure disorder, seizures that generalize secondarily and a younger age at the onset of epilepsy. Kerne and Chapieski further linked higher levels of parental anxiety with lower levels of parents' education and a family history of epilepsy.

2.2.4.6 The emotional impact of a chronic condition and of specifically epilepsy.

Specific emotions appear to be attached to the diagnosis if patients know from the onset that the condition is chronic and that they will have to deal with it on a long-term basis. Ferro and Boyle (2013) searched databases on asthma, cerebral palsy, diabetes, epilepsy and juvenile arthritis, and found that youth with a chronic illness compromise their self-concept. Cousino and Hazen (2013) conducted a meta-analysis of 13 studies and qualitative analysis of 96 studies on parenting stress among caregivers of children with asthma, cancer, cystic fibrosis, diabetes, epilepsy, juvenile rheumatoid arthritis and sickle cell disease. These caregivers reported significant higher stress levels than the stress levels of caregivers of healthy children. Their qualitative analysis revealed a higher incidence of general parenting stress associated with larger parental responsibility for treatment management; furthermore, this was not related to the duration and severity of the illness. Higher parenting stress levels are related to poorer psychological adjustment in children with chronic illness and that of their caregivers (Cousino & Hazen, 2013). A chronic condition has a further emotional impact on family functioning, caregiver support and quality of life. Nabors et al. (2013) found that in the United States, family functioning mediated the relationship between family hardiness and caregiver anxiety as a resilience factor that reduced caregiver anxiety. They further suggested that future research should focus on the implementation of effective interventions to improve caregiver support, especially when a child needs to be hospitalized.

A Canadian study by Novak, Costantini, Schneider, and Beanlands (2013) focused on chronic kidney disease. They found that a better understanding of self-management in chronic illness supports patient-provider collaboration, improves patient care and patient-health care satisfaction, and results in better quality of life and clinical outcomes for patients and families.

Children with a chronic illness experience a variety of emotions and other aspects that influence their emotional state. Findings from qualitative studies on children's experience of feeling different when living with long-term conditions, in particular, epilepsy, asthma, and diabetes revealed three common themes: participation in everyday life such as restrictions and adjustments; treatment regimens including constraining and enabling; and communication that involves disclosure, stigma and support (Lambert & Keogh, 2015). The study further revealed that children felt different socially and physically, and struggled to create a balance between the dilemma of acting and feeling normal or being, revealing and feeling different.

Research has shown that adolescents with epilepsy typically experience a variety of emotions including anxiety, depression, fear of having seizures, fear of feeling 'out of control', fear of being dependent on adults for care when their peers are becoming more independent and fear of being hospitalized (Siqueira et al., 2015). The patients' challenges included difficulties in coping with medication and side-effects, a lack of understanding from friends, learning difficulties, underachievement at school, abnormal brain functioning, low self-esteem, immaturity, rejection and overprotective parents (Camfield & Camfield, 2014; Solomon & McHale, 2012; Siqueira et al., 2015).

Gebauer-Bukurov, Markovic, Sekulic and Bozic (2015) in a study on 90 well-functioning adolescents with epilepsy found that adolescents with regular seizures and multiple seizure types had impaired social skills. Gebauer-Bukurov et al. recommended social skills and competence in clinical practice be further investigated. Adjustment issues vary considerably from person to person depending on the type and frequency of seizures, the patient's age and developmental phase, and the patient's level of confidence and need for emotional support (Solomon & McHale, 2012). Adult outcomes after childhood-onset epilepsy can be complicated as seizure types and intensity are diverse, and different aspects influence social outcomes and comorbidities often occur (Camfield & Camfield, 2014).

Corrigan, Broome & Dorris (2016) found that psychosocial interventions can improve children's knowledge about epilepsy, and that self-management skills and cognitive behavioural therapy can be effective in managing anxiety and a low mood. Future career prospects are a normal stressor for healthy adolescents and so much more for an adolescent with epilepsy as it can impact on these adolescents' independent functioning and wellbeing. Seizures and taking anti-epileptic medication may lead to a sense of physical incompetence; consequently, an adolescent with epilepsy may withdraw socially and emotionally (Engel, 2013). To deal effectively with these challenges, patients and their families develop a variety of coping strategies to focus on the practical aspects and emotions brought about by epilepsy. The researcher is of the opinion that emotional adjustment is critical.

2.2.4.7 Stigma.

People experience a stigma attached to the diagnosis of epilepsy and the labels, patient and seriously ill, may disrupt relationships (Jacoby, Snape, & Baker, 2005). Not only do those with epilepsy have to cope with the complex demands of a chronic illness but also social stigma and prejudice in physical activities, employment and education (De Boer, Mula & Sander, 2008; Engel, 2013). People have reported negative attitudes toward epilepsy in different countries; in fact, there is a well-documented association between epilepsy and stigma (Al-Khateeb & Al-Khateeb, 2014; Benson, Lambert, Gallagher, Shahwan, & Austin, 2015; Benson et al., 2016; Engel; Wang et al., 2015). People encounter the fear of stigma, exclusion, rejection and restrictions as barriers to disclose the diagnosis of epilepsy (Benson, Lambert et al., 2015; Benson, O'Toole et al., 2015). In a survey on the quality of life in adolescents with epilepsy, Zamani et al. (2014) found that the diagnosis could negatively affect the social affairs and networking of patients. Seizure frequency and type, family environment, adverse effects of antiepileptic drugs, school, an introverted personality, actual discrimination, problem-solving and society influence the relation between epilepsy and the perceived stigma (Ryu et al., 2015). Rood et al. (2014), in a study on the perceived stigma of children with newly diagnosed epilepsy and their caregivers, found a decrease in epilepsy-related stigma over time.

Knowledge about epilepsy influences the perceived stigma. In a cross-sectional multicentre study involving adolescents with epilepsy and their mothers from 25 hospitals in Korea, Ryu et al. (2015) assessed their level of knowledge of epilepsy. The results demonstrated adolescents' knowledge about epilepsy, concealment behaviour of the mother and receiving poly-therapy significantly influenced the adolescent's perception of stigma, self-esteem and psychosocial health. Ryu et al. found that the perception of stigma of the parents correlates with the child's depression and emphasized the importance of the role of the family in the development of children's perceptions of stigma. Teachers and educators involved in children's lives lack sufficient knowledge on how to support children with epilepsy. A community-based study conducted in South-West Nigeria found that if secondary teachers receive health education training on illnesses, it could lessen prejudice and increase acceptance of children with epilepsy (Mustapha, Odu, & Akande, 2013). Espinola-Nadurille et al. (2014) found that interpersonal, internalized and institutional stigma prevents patients with epilepsy from participating in employment and school, and reduces their opportunities to establish couple and peer relationships. The researchers suggested treatment for epilepsy should include psychosocial programmes on stigma.

How people view epilepsy tends to play a role in the experience of the stigma attached to it. Joachim and Acorn (2016) found that when people examined chronic illness through a stigma lens, the focus fell on the manner in which the individual suffers from the stigma. When people examined chronic illness through a normal lens, the focus fell on the manner in which the individual achieves normality despite having a chronic condition. Children with epilepsy have a desire for normality (Harden, Black, & Chin, 2016). To have a chronic illness may be automatically accompanied by loss in social value (Heijnders & Van Der Meij, 2006). If peers tease children with epilepsy, it can leave deep emotional wounds that upset the child's emotional and social development, and are humiliating and painful. Early assessment for psychosocial problems and appropriate interventions are beneficial for patients and families, and important during periods of transition such as that from adolescence to adulthood.

2.2.5 Psychosocial Issues

The stigma and psychosocial challenges that are associated with epilepsy seem to be a burden that affects the quality of life of those diagnosed with epilepsy. Psychosocial issues include peer acceptance and social isolation (Thomson, Fayed, Sedarous, & Ronen, 2014). Young people with epilepsy are less likely to reach the level of independence accomplished by their peers. Furthermore, family communication can affect the psychosocial wellbeing of children with chronic illnesses and that of their parents (Kerne & Chapieski, 2015; O'Toole et al., 2015). When children with epilepsy enter adulthood, they tend to face many challenges on a psychosocial level. Adult life for a person diagnosed with epilepsy is often unsatisfactory as it is associated with high rates of unemployment, unfinished education, social isolation, poverty, psychiatric problems, unwanted pregnancies and various health concerns (Camfield & Camfield, 2014; Engel, 2013; Nabbout et al., 2017). Sociodemographic, clinical and behavioural variables play a role in self-concept (Ferro, Ferro, & Boyle, 2012). Al-Khateeb and Al-Khateeb (2014) found that in nine out of 22 Arab countries the most commonly measured parameters of psychosocial aspects of epilepsy appear to be social and emotional, and are related to employment, knowledge, attitudes and quality of life (Al-Khateeb & Al-Khateeb, 2014).

Every childhood illness has unique characteristics. The following biopsychosocial characteristics occur across all illnesses: psychosocial well-being and development of the patient; financial, emotional and time-demand challenges on the family system; family and social structure changes to accommodate chronic illness demands; maladaptive family patterns that interfere with illness management; and disruption of peer and school functioning (Wood, 1996). A review of existing literature depicts children with epilepsy and their families as vulnerable, at risk and a problem. It appears that previous research has focused on these families from this angle and on individuals, and has not really considered the system and processes in the families. Previous research has tended to comment on pathology and problems experienced in families with an adolescent diagnosed with epilepsy and not enough on functioning and coping.

2.3 Adolescent Epilepsy and Family Processes

In this section, research related to epilepsy during adolescence and the impact on the family and families living with chronic illness is discussed.

2.3.1 Epilepsy During Adolescence and the Impact on the Family

In a study on the perceived burden of epilepsy and the impact on the quality of life of adolescents and their families, Cianchetti et al. (2015) found that parental concerns are correlated with a deterioration of quality of life. In a comparative study, Bompori, Niakas, Nakou, Siamopoulou-Mavridou and Tzoufi (2014) found that epilepsy had a more significant effect on adolescents and was associated with a poor health-related quality of life when compared to healthy children. Results further indicated that the severity of the clinical presentation affects the health-related quality of life of children with epilepsy and their parents had poorer physical and mental health (Lv et al., 2009). Epilepsy seems to impair all aspects of one’s quality of life. The impact on children and parents, and not on the family processes have been emphasized in the latter studies. Carbone, Zebrack, Plegue, Joshi, and Shellhaas (2013) revealed better self-reported parent adherence is correlated with higher epilepsy expectations, knowledge and more medication. O’Toole et al. (2015) suggested that enhancing families’ knowledge of epilepsy and treatment may improve adherence. A systematic review conducted by these researchers on family communication in the context of paediatric epilepsy did not identify any research on specific communication strategies adopted by families living with childhood epilepsy. O’Toole et al. further found that to talk about epilepsy with family members had positive consequences and the main constraint to communication parents experienced was an unwillingness to use the word, epilepsy because of the perceived negative social connotations. Even when seizures are well controlled, it appears as though parental fears and expectations, stigma associated with the illness, and continuous parental and patient anxiety in relation to the possible reoccurrence of seizures contributes to a long-term process of adjustment (Appleton & Gibbs, 2014). In a case-control study on 42 patients with epilepsy, Wang et al. (2015) found that patients had higher levels of depression and anxiety, dissatisfaction with family functioning and marriage quality, and less social support in comparison to healthy controls. Wang et al. further reported that emotional support outside and within the family promoted marital quality and family cohesion, depression had a decreasing effect on family adjustment and support lowered levels of anxiety in patients with epilepsy. Promoting family and emotional support and lowering depression may improve the marital quality and family functioning of patients with epilepsy and assist in decreasing anxiety. Family functioning might be an important treatment target to enhance coping in patients with epilepsy (Wang et al., 2015).

Concerns of family members and caregivers include reactions of family members towards the child with epilepsy, parental awareness regarding societal stereotypes, social stigma, engagement of parents with the child, negative emotions and fear regarding the wellbeing of the child (Bompori et al., 2014). Constructive responses to the child's illness are essential to enable them to achieve the necessary developmental tasks during adolescence (Appleton & Gibbs, 2014). A plethora of research has been conducted on the parent's reaction to the diagnosis of epilepsy. A longitudinal study conducted by Wu, Follansbee-Junger, Rausch and Modi (2014) that included 124 children with new-onset epilepsy focused on parent and family stress factors that predict health-related quality found that higher levels of general and epilepsy-specific parental and family stress, perceived stigma, fears and concerns had a negative impact on general child and epilepsy-specific health-related quality of life in addition to demographic and disease factors. The researchers recommended the implementation of psychosocial interventions within the first year after diagnosis to enhance the health-related quality of life by exploring the following: stress experienced by family members and parents, overall coping and guidance on how to manage epilepsy. Interventions need to focus on perceived stigmas, adherence, fears, concerns, and how to enhance parental management of stress, fears, concerns and perceived stigma (Wu et al., 2014). Epilepsy has a pejorative social meaning and consequently, it is possible to plan the health-illness transition experience around the perceptions of the parents in relation to the meaning of their child's illness within a social context (Engel, 2013). It is evident from the literature that further research is needed on the processes and experience of the families of adolescents diagnosed with epilepsy.

The effect and impact of a diagnosis of epilepsy in which sample groups comprised patients and their parents only has been investigated extensively (Chiou & Hseih, 2008; Cushner-Weinstein et al., 2008; Iseri, Ozten, & Aker, 2006; Rodenburg, Meijer, Deković, & Aldenkamp, 2005; Rodenburg, Meijer, Dekovic, & Aldenkamp, 2007; Wirrel, Wood, Hamiwka, & Sherman, 2008). These studies did not focus on the process and functioning of the family as a whole, but on the impact on parents and patients only. Chiou and Hseih found in their sample group of 48 children with epilepsy and 54 with asthma that levels of parenting stress were higher in caregivers of children with epilepsy than in caregivers of children with asthma. Cushner-Weinstein et al. found that almost half of the caregivers of parents and children with epilepsy reported elevated stress levels. Iseri et al. found that post-traumatic stress syndrome symptoms were common in caregivers of children with epilepsy in a sample of 77 mothers and three fathers. Rodenburg et al. demonstrated that higher levels of parenting stress were associated with the child’s functional status and temperament, and depression experienced by parents in a sample of 91 parents. Rodenburg et al. also found that family cohesion, social support, emotion- focused coping and problem-focused coping play a role in stress experienced by parents. Wirrel et al. found evidence that epilepsy, and child and family characteristics increased maternal stress in their sample of 52 mothers of children with intractable epilepsy. Hoare and Kerley (1992) found that 14 caregivers from a seizure clinic believed that they had no concerns and would not benefit from group counselling. Lewis et al. (1991) found a significant decrease in anxiety of 365 parents after an intervention for caregivers. Tieffenberg et al. (2000) found that overall post-intervention caregivers of 188 and 167 children with asthma and epilepsy, experienced improvements in concerns, anxiety and knowledge about asthma and epilepsy.

2.3.2 Families Living with Chronic Illness

Support or the lack thereof plays an essential role in the experience and coping of families living with a chronic illness (Ferro & Boyle, 2015; Rolland, 2011). A study in Scandinavia that conducted repeated qualitative narrative interviews with seven families found that to live as a family in the midst of chronic illness is an ongoing process where the family members co-create a context for living with illness and create alternative means for everyday life (Arestedt et al., 2014). All family members seem to benefit from receiving support and sharing experiences in this changed situation. It is possible that perceptions include specific emotional themes during the chronic phase of epilepsy. In an exploratory qualitative study on patients and their family members in the chronic phase of chronic obstructive pulmonary disease, individual interviews to explore participants' perspectives were conducted and thematic analysis performed (Gabriel, Figueiredo, Jácome, Cruz, & Marques, 2014). Results indicated complex interactions between the experience of living with chronic obstructive pulmonary disease, social support, social roles, communication patterns and emotional states in the family. This highlights the importance of developing family-based interventions to facilitate functional adjustment. The major themes that emerged from the patients' perspective included: the impact of the disease symptoms on the daily living of family members and patients; families support in an overprotective manner; challenges in the communication of couples; a sense of identity loss; a fear that the chronic disease will progress; and coping resources. The themes that emerged from the family's perspective included: restrictions in the family's social life; emotional distress related to chronic obstructive pulmonary disease exacerbations; stress in couple relationships; financial stressors; and coping resources.

Various studies have commented on how families differ among themselves in relation to their experience with different chronic illnesses. The following three studies highlight that families with a child diagnosed with a chronic illness might experience psychological problems and that psychotherapy can assist in the management thereof. Research conducted on an American palliative care patient sample revealed that cohesiveness, conflict resolution and expressiveness appear to be meaningful dimensions by which patient perceptions of family functioning can be classified (Schuler et al., 2014). The researchers further suggested that such families might benefit from family therapy. A further study that focused on the psychological issues of adjustment, maternal distress and family functioning in children with obstetrical brachial plexus palsy found that these children and their mothers are at increased risk of experiencing a variety of psychological problems (Alyanak, Kilinçaslan, Kutlu, Bozkurt, & Aydin, 2013). The researchers recommended that professionals should be aware of the psychological adjustment of these children and their caregivers and should refer them for further psychological support. Johnson and Simpson (2013) revealed that caring for children with autism spectrum disorder in the United States is stressful and challenging for the mothers and these mothers are at risk of experiencing stress and isolation when negotiating family functions with the children's fathers. The researchers suggested that healthcare practitioners should assess family functioning and stress so as to anticipate different needs based on the father's involvement in decision-making and marital status.

Knafl et al. (2013) noted the importance of understanding patterns of family response to childhood chronic illness so as to enable a more comprehensive understanding of the influence of these patterns on child and family functioning. Popp, Robinson, Britner and Blank (2014) assessed the experience of parents who have a child diagnosed with a chronic illness (type 1 diabetes or asthma) where the children's narratives mirror these experiences. They found that 41% of parents had unresolved feelings about their child's diagnosis regardless of the time that had lapsed since diagnosis. The parents reported lower family functioning and the children acknowledged family conflict. The researchers recommended that future work should consider interventions related to the expression of emotion and family communication. A sample of 76 parents of Australian adolescents with Type 1 diabetes participated in a study on parental perceptions of child health and family functioning (Moore, Hackworth, Hamilton, Northam, & Cameron, 2013). Results showed that parent-reported family conflict, disease effects, family dynamics and parental stress were high, and focus should be placed on family functioning and relationships in adolescent chronic disease management.

Choi (2015) employed a mixed methods approach in a study on 147 parents of children with Down syndrome in Korea that explored family and parental adjustment, and shed light on life with a Korean child with Down syndrome. Quantitative data, namely, family adjustment scores indicated average family functioning, and that financial status was an important variable in understanding family and parental adjustment. Family problem-solving, coping communication, condition management ability and family hardiness can best explain family adaptation. Choi found that family strains and hardiness were the family factors with the most influence on family adjustment. Qualitative data revealed that family life encompassed positive and negative aspects. This concurs with research conducted on resilience in families with a child with cancer (Greeff, Vansteenwegen, & Geldhof, 2014). The researchers employed a cross-sectional survey research design, and children and parents completed self-report questionnaires. The most significant results from the children's data were that better family adjustment is improved by connectedness within the family, having family routines, experiencing a feeling of control over life events, practising supportive and positive communication, redefining crisis situations and having a passive appraisal of crisis situations.

2.4 Conclusion

According to Hauser (1990), although some researchers have explored the individual's perceptions of the family, only a few have conducted family interviews from the perspective of the family and included the family processes and coping strategies.

Healthcare providers have long been aware of the impact of treating chronically ill adolescents in response to the illness on the family, the course of the illness and the compliance of patients. The response to illness and processes in families often occur simultaneously. This, in turn, affects the course of the illness course and whether the adolescent complies with the treatment (Hauser, 1990). The systemic approach of Minuchin emphasizes the importance of direct observations of whole families to gain knowledge on how families cope with the illnesses of specific family members (Hauser, 1990; Minuchin, 1974). In this chapter, the existing literature with a specific focus on epilepsy, adolescence, family processes, psychological implications, psychosocial issues, emotional issues, and family processes linked with adolescence and the experience of epilepsy was reviewed. Family processes and in particular, family functioning, family satisfaction, family hardiness, and family processes and functioning in conjunction with chronic illness were reviewed. It appears as though family processes can differ across family systems and families undergo challenges when a diagnosis of epilepsy is made during adolescence. If the adolescent is satisfied with how he or she experiences the family, it can have a positive effect on how the adolescent experiences the challenges of adolescence. Families low in hardiness tend to feel weak when they face stressors and tend to be more passive in their approach to the changing events in their lives.

Adolescents with epilepsy often experience a low quality of life, experience challenges to communicate effectively and are prone to suffer from a variety of emotional disorders and behavioural problems. Families with a child with epilepsy generally do not fare well; furthermore, the diagnosis of epilepsy affects the whole family with a range of family factors including problems with family functioning, a higher prevalence of depression among mothers and caregivers, and poorer parent-child relationship quality.

Treating medical and healthcare practitioners play an important role in the adjustment, coping and managing of adolescents with epilepsy, and compliance with the treatment. It seems that some people deal with the emotions involved in different ways and that success at developing these skills and coping with a chronic condition depends on the condition, the person that contracted it, and the resources available.

The review highlighted the following: Children with epilepsy and their families are vulnerable and at risk for possible challenges with psychological and health issues. Previous research has espoused the vulnerability of families and individuals within these families while commenting much on pathology and problems experienced in families. The current study focused on the system, processes, functioning and coping in the families.

It is evident from the literature that a diagnosis of epilepsy has particular challenges on practical, physical and emotional levels. Furthermore, it is especially challenging for a family to deal with this diagnosis when their child is an adolescent. Further research is needed on the processes and experiences of the families of adolescents diagnosed with epilepsy. The theoretical approach and paradigmatic point of departure of the present study is explained in the following chapter.

CHAPTER 3: PARADIGMATIC POINT OF DEPARTURE AND THEORETICAL APPROACH

In this chapter, the paradigmatic point of departure and theoretical approach employed in the study are explained. A description of positivism, post positivism ontology with critical realism, constructivism, social constructivism and social constructionism follows. Accordingly, critical realism, the paradigmatic point of departure, is situated so as to compare realist and relativist paradigms. Family systems theory from a position of critical realism was employed to explore how families experience living with an adolescent diagnosed with epilepsy as well as the family processes reported by patients and family members.

3.1 Positivism

Positivism is the oldest and most widely used philosophical outlook on science (Becvar & Becvar, 2014; Chilisa & Kawulich, 2012; Neuman, 2014). Positivism originated from a 19th century school of thought from Auguste Comte, the founder of sociology. It is associated with many social theories and proposes that scientific methods are the only way to establish truth, objective reality and true knowledge (Chilisa & Kawulich, 2012; Comte, 1974; Neuman, 2014). Positivist researchers prefer precise quantitative data and seek rigorous, exact measures and favour objective research (Neuman, 2014). Positivism is concerned with the positive application of knowledge to assist human progress. Furthermore, it stands in contrast to social constructionism with its sceptical rejection of expert knowledge claims (Giddens, 2013; Kolakowski, 1972).

3.2 Post-Positivism

A number of post positivist positions were developed in the human and health sciences (Groff, 2004). Social constructionism and critical realism are two of the most prominent types (Alexander, 2014; Cruickshank, 2012). Critical realism acknowledges that error can be part of observations and that modifications of theories can occur (Trochin, as cited in Chilisa & Kawulich, 2012). Critical realists recognize that the observer's worldview and biases influence observations. Furthermore, these observations are theory-laden and one cannot comprehend reality with certainty (Chilisa & Kawulich, 2012). Researchers are able to use multiple observations, measures and triangulation of data to obtain a clearer understanding of reality in an attempt to achieve objectivity. This is a more critical approach than positivism. Although realists reject positivism, they agree that one can apply knowledge positively to assist technical and medical progress (Bhaskar, 2013).

3.3 Constructivism

Constructivism, which is viewed as an approach to qualitative research, focuses on what can be known in the external world and on how our innate mental and sensory structures work (Becvar & Becvar, 2014; Creswell, 2014; Kelly, 1955; Maturana & Varela, 1987; Vall Castello, 2013). It is a theory of knowledge that examines the understandings and knowledge of the world as well as understanding, meaning and significance developed in conjunction with other human beings (Amineh & Asl, 2015; Vall Castello, 2013; Willig, 2016). Constructivists believe that people acquire subjective meanings of their experiences and construct their own reality, which originates from their internal cognitive or belief system (Creswell, 2014; Keeney, 1981, 2017; Keeney & Ross, 1983, 1985). The ontology of constructivist research entails multiple realities. Furthermore, the epistemology may include researchers visiting participants at their sites to collect data (Creswell & Clark, 2017; Lincoln & Guba, 2013; Willig, 2016). According to constructivism, identity includes personal features and moral character is an achievement of the mind over which people have authorship (Vall Castello, 2013). Any perception is only a partial arc of a more recursive cycle, pattern or greater complex whole. Moreover, true objectivity or reality does not exist (Carich & Willingham, 1987).

3.4 Social Constructionism

It is possible to base social constructionism on a relativist epistemology, which proposes that all knowledge is relative to one's location within a set of social norms (Burr, 1995; Burr, 1998; Cruickshank, 2012). Social constructionists attempt to nurture a sceptical attitude towards expert knowledge claims and assume that the reality experienced is inseparable from society's pre-packaged thoughts (Becvar & Becvar, 2014; Burr, 2018; Cruickshank, 2012; Forrester & Sullivan, 2018). According to social constructionism, knowledge is socially constructed and narratives allow people to organize and communicate knowledge that is socially and culturally created (Gergen, 1998). Identity is viewed as an achievement of relation with greater emphasis on context, social constructions of problems and creation of narratives (Becvar & Becvar, 2014; Vall Castello, 2013; Willig, 1998). Social constructionists endorse a relativist rejection of truth and are of the opinion that the task of research is to nurture a scepticism that undermines any claim of positive truth (Becvar & Becvar, 2014). In essence, social constructionists focus on tacit real ethical principles and realist assumptions about research that are contrary to their relativism (Burr, 2018; Gergen, 1998; Vall Castello, 2013).

3.5 Critical Realism

Constructivism and positivism are the two opposite philosophical orientations of the nature of reality. Constructivism focuses on a reality, which is relative to one's position within the social system whereas positivism makes claims about absolute truth, causal laws and regularities (Cruickshank, 2012; Forrester & Sullivan, 2018). Critical realism fits in between the extremes of the subjective, mind-dependent, and the objective, mind-independent nature of reality that is assumed by constructivism and positivism, respectively (Allana & Clark, 2018; Archer, Bhaskar, Collier, Lawson, & Norrie, 2013; Danermark, Ekstrom, & Jakobsen, 2005; Hartwig, 2007; Losch, 2009; Steele, 2005).

3.5.1 Critical Realism in General

Critical realism, which was originally described by Bhaskar (2013), views reality as layered (realist ontology) and endeavours to explore causative mechanisms of what researchers observe and experience (Bhaskar, 2013; Walsh & Evans, 2014).Critical realism accepts that reality can be best understood by investigating multiple outlooks so as to develop deeper levels of understanding and exploration (Halcomb & Hickman, 2015). Accordingly, this worldview is well-suited to mixed methods research. Critical realists believe that there is an independent reality apart from the human mind. However, the only access we have to reality is epistemological by establishing meaning (Pocock, 2015). Critical realists believe that knowledge is positively applied and propose basing causal explanations on empirical regularities with reference to unobservable structures (Cruickshank, 2012; Forrester & Sullivan, 2018; Willig, 2013).

In critical realism, language constructs our social realities. Moreover, constraints and possibilities in the material world can shape these constructions. An advantage of employing a critical realist approach is that the analysis can include relationships between people's material conditions and discursive practices (Sims-Schouten, Riley, & Willig, 2007). This implies that the analysis will not be without meaning unless interpreted discursively. Critical realism combines realist and constructionist positions to argue that while meaning is made during interaction, non-discursive elements also affect the meaning (Sims-Schouten et al., 2007). Critical realism correlates with post-positivist assumptions where the researcher aims to describe an objective reality while looking from the 'outside'. However, researchers concede that it is not possible to be completely objective even though it is approachable (Wagner, Kawulich, & Garner, 2012).

3.5.2 Critical Realism and Mixed Methods Research

A mixed methods approach, which attempts to develop a comprehensive understanding of the phenomenon under investigation, can explore health conditions through multiple dimensions; thus, making it effective for complex health research (Allana & Clark, 2018; Chiang-Hanisko, Newman, Dyess, Piyakong, & Liehr, 2016). Using a critical realist approach in mixed methods research offers a sound ontological basis, which justifies and supports the use of different methods to explore the same phenomenon (Zachariadis, Scott, & Barrett, 2013).

This study is not free of values. Therefore, a proclaimed philosophical position is important and the researcher's beliefs and values have an influence on this study (Becvar & Becvar, 2014; Grove, Gray, & Burns, 2015). It is important to recognize that the theories, hypothesis and background knowledge of the researcher may strongly influence what and how observations take place as well as what the outcome is (Wagner et al., 2012). This is further explained in Chapter 6.

The ontological assumption proposes there are many realities or truths. It further subscribes to the epistemological assumption that knowledge is socially constructed and that the participants and researcher collaborate in providing an in-depth description of the experiences of the participants (Willig, 2013). When the researcher conducted interviews, she became part of each family's system by being critical, interpretive and curious. Consequently, the family's embedded reality was investigated and co-constructed by the researcher (Wagner et al., 2012). This viewpoint links critical realism and systems theory. Observations can involve error, modifications of theories can take place and reality is uncertain (Forrester & Sullivan, 2018). The biases and worldview of researchers influence observations and are laden with theory (Wagner et al., 2012). The researcher looked at the family as a system and at the processes in each family. This is linked to each family's reality that the researcher attempted to understand, even though imperfectly.

3.6 Systems Theory

The theoretical framework of this study was derived from general systems theory; specifically, the principles of family systems theory were applied.

3.6.1 General Systems Theory and Cybernetics

Systems theory encompasses both cybernetics and general systems theory. Furthermore, it focuses on the relationship between elements rather than on the elements themselves (Becvar & Becvar, 2014; Goldenberg & Goldenberg, 2013). It proposes that a system is a set of interdependent components that form an internally organized whole that operates as one in relation to its environment and to other systems. In addition, it receives feedback so as to maintain a system's function (Hanson, 2013; Poole, 2014).

Although families consist of individual members, a comprehension of the behaviour of any one person in the family can only be understood in the context of the entire unit's behaviour (Becvar & Becvar, 2017; Broderick, 1993; Fleming, 2003; Miklowitz, 1994). If a system represents a set of units that are in some consistent relationship to one another, it will organize itself around the relationships. Moreover, the system's parts will interact with each other in predictable ways. To understanding a family as a system, one must progress from the family as a whole to its parts. (Becvar & Becvar, 2014; Skyttner, 2006). The family is superordinate to the attributes, behaviour, needs and/or wishes of any individual within this system (Miklowitz, 1994). Viewing individual members results in a limited perspective of the family holistically as each part is recursively connected through calibrated feedback loops (Keeney, 2017; Keeney & Ross, 1985; Smith-Acuna, 2010). Theorists view systems as wholes, and as homeostatic and balanced entities (Bateson, 1979, 2000; Laszlo, 1996; Nichols, 2010; Von Bertalanffy, 1981).

Systems theory or cybernetics focuses on relationships between individuals and does not view problems in isolation (Becvar & Becvar, 2014). This broader holistic approach focuses on the complexity, interactivity and organization of organisms. It further recognizes that context and process give meaning to events (Fleming, 2003; Hanson, 2013; Von Bertanlanffy, 1972). Here-and-now interactions receive more attention than incidents that happened in the past, observers participate in creating their own reality and the observed as well as the observer influence the process of mutual exchange (Becvar & Becvar, 2014).

Systems theory supports the assumption that all kinds of systems, namely, concrete, conceptual, abstract, natural and fabricated systems have characteristics in common, regardless of their internal nature (Becvar & Becvar, 2017). The system works with equifinality in that the organization of the system plays an important role in determining reactions. In relation to social contexts, the focus is on interwoven patterns, relationships, physical entities, time factors to which people relate, and any social and physical setting in which someone observes the particular observed part (Carich & Willingham, 1987). Systems theorists claim that behaviour serves a purpose or function within the system (Goldenberg & Goldenberg, 2013). According to Keeney (2017), systemic theorists view observation as part of the context; the latter can be society, family or an individual. Systems theory postulates that cause and effect cannot be separated; the implication thereof is that when a person is born into a family with epilepsy, to some extent, everybody in that family has 'epilepsy' (Seligman & Darling, 2007).

From the perspective of first-order cybernetics, reality is seen as out there. The observer is unable to observe reality without being influenced and the researcher remains an external observer (Becvar & Becvar, 2014, 2017). From the perspective of second-order cybernetics, there is no outside, independent observer of a system because any person who attempts to change and observe a system is a participant who influences and, in turn, is influenced by that system (Goldenberg & Goldenberg, 2013).

3.6.2 Families as Systems

In this section, various systemic family theories and elements of family systems theory are discussed.In this study, the researcher utilized family systems theory based on the foundations of Bowen (1976) and Minuchin (1974).

3.6.2.1 Bowen family systems theory.

Bowen, the developer of the Bowen family systems theory, conceptualized the family as an emotional unit, a network of interlocking relationships, which can be best explained when analysed within a multigenerational or historical framework (Goldenberg & Goldenberg, 2013). According to Bowen (1976), the reciprocal functioning of all the members of the family contributes to the emotional intensity of the patient. Furthermore, current family problems and patterns tend to repeat over generations (Haefner, 2014). Bowen’s theory, which comprises eight interlocking states that describe the chronic emotional anxiety present in family relationships, views chronic anxiety as the source of family dysfunction (Haefner, 2014). Research from Bowen’s perspective focuses on the degree of differentiation of self and emotional fusion, which concerns the ability of individuals to distinguish themselves from the family of origin on an intellectual and personal level (Bowen 1976, 1985). Differentiation of self occurs when someone can function autonomously, yet remains emotionally connected to important relationships (Becvar & Becvar, 2014; Bowen, 1976). Autonomy occurs when someone has the ability to clearly think through a situation and is able to separate emotions from rational thought (Bowen, 1976; Haefner, 2014). In healthy families, children are allowed to develop their own personal autonomy and are capable of functioning in different situations. Bowen perceived stress to be a normal part of living and believed symptoms can evolve under chronic stress conditions. Consequently, the presence of symptoms is not viewed as dysfunctional (Becvar & Becvar, 2014). Bowen proposed that people with high chronic anxiety need to manage it by employing the following four means: marital conflict, emotional and/or health problems, emotional or health problems of a child, and/or, triangulation of other people into the relationship (Bowen, 1985; Haefner, 2014). Emotional fusion concerns a person’s reactions within a relationship and people in a fused relationship react emotionally without reasoning or talking about choices with the other person (Haefner, 2014). Highly fused relationships create significant anxiety as a person may fear rejection if it is possible the independent decision will cause emotional separateness. According to Bowen (1976), triangling occurs when the tension and anxiety that two people experience is passed on to a third person in the family; for example, when a couple can communicate safely when they involve a third person and anxiety is shifted from their relationship to the third party (Bowen, 1985; Haefner, 2014).

According to Bowen (1976, 1985) and Haefner (2014), additional concepts of Bowen family systems theory include *the nuclear family emotional system* where dysfunctional fusion leads to marital conflict, polarization of a spouse and/or psychological impairment in a child; *multigenerational transition processes* where roles, themes and coping strategies are passed on from one generation to the next; *family projection processes* where parents transfer their level of differentiation and anxiety to their children, and the child becomes the identified patient; s*ibling position* where birth order affects personality characteristic development; *emotional cut-off* where family members withdraw emotionally to regulate unresolved attachment and break emotional ties; and *societal regression,* where forces of individualization and differentiation are opposed. While some relationships function in a way that is overly close or fused with no room for the needs of the individual, other relationships have no connection at all (Bowen, 1985).

3.6.2.2 Minuchin's family systems theory.

The concept of hierarchies describes how families organise themselves into different smaller subsystems that together comprise the larger family system (Fleming, 2003; Minuchin, 1974). Minuchin referred to the notion that most systems are supra systems and subsystems at the same time as a holon. The subsystems of interest include marital, parental and sibling subsystems. Parental-sibling subsystems play an important role in terms of hierarchy and power. In healthy families, parent-children boundaries are both semi-diffuse and clear, and allow parents to interact together with some degree of authority in negotiating between the ways of parenting and goals. The parents allow autonomous peer and sibling interactions (Minuchin, 1974).

3.6.2.3 Families as open systems.

In open systems, the focus is on the processes that track those processes over time to determine if a pattern exists, and if the systems allow information to flow back and forth (Broderick, 1993). Systems can change over time through input, output and interactions. One can view society as the environmental context in family systems and the individual family members as the component units. The context of environment provides the definitional framework for adjustment (Wedemeyer & Grotevant, 1982). The family depends on a wider environment so as to adapt, change, grow and sustain itself (Becvar & Becvar, 2017; Broderick, 1993).

3.6.2.4 Family processes and systems.

When focusing on family processes, it is noteworthy to take cognizance of the following in relation to systems: Communication and interaction patterns, separateness and connectedness, loyalty and independence, and adjustment to stress in the context of the whole as opposed to the individual in isolation (Christian, 2006; DeFrain, Asay, & Olson, 2009; Fleming, 2003). People learn skills from their families that enable them to function in larger and more formal settings such as school and the workplace, and this enables an understanding of how the larger world will interact with them (Christian, 2006). To understand a family, it is necessary to assess patterns of interaction with the emphasis on *what* is happening and not on *why* it is happening (Becvar & Becvar, 2014). Families function in close relationships and interact “to carry out the daily challenges and tasks of life, as well as adjusting to the developmental needs of its members” (Fleming, 2003, p. 643). A family is a purposeful system with goals.

3.6.2.5 Mutual causality.

Circular or mutual causality is important in family systems theory where observations focus on the mutual impact and effect of actions and reactions (Bateson, 1979, 2000; Becvar & Becvar, 2017; Laszlo, 1996; Lederer & Jackson, 1968; Von Bertalanffy, 1981). Furthermore, patterns of interaction in a family can create or resist change. Moreover, it is possible to see the structure of a family in its interactions (Fleming, 2003). Each change or action affects every other member of the family and each family has certain rules that are peculiar to it and that are self-regulating (Fleming, 2003). Subsystems must maintain their boundaries for families to function well. Each family system constantly adapts to maintain itself in response to its environment and members despite change or resistance (Bateson, 1979, 2000; Becvar & Becvar, 2017; Von Bertalanffy, 1981).

3.6.2.6 Wholeness and interdependence.

Wholeness and interdependence are important in systems theory and are discussed in section 3.7.1.1. Family systems are self-reflexive, have the ability to have themselves and their behaviour as the object of examination and target of explanation, and establish their own goals (Becvar & Becvar, 2017). Supra systems define families in relation to their extended families, geographic regions, racial and ethnic subcultures, and create a hierarchy (Minuchin, 1974).

3.6.2.7 Boundaries.

Boundaries form emotional barriers that protect and improve the integrity of systems. Furthermore, consistent boundaries play a role in establishing functional systems (Segrin & Flora, 2011). Boundaries form the border between the system and its external environment, often establish the hierarchical structure, and define who participates and how (Minuchin, 1974; Segrin & Flora, 2011; Smith-Acuna, 2010). To ensure proper family functioning, subsystems must form distinct boundaries and be defined well enough to allow subsystem members to carry out their functions without interference, but must allow contact between members of the subsystem and others (Beavers, 1977; Minuchin, 1974). Boundaries between the outside world and the family system exist on a continuum from fluid, enmeshed to disengaged families (Miklowitz, 1994; Minuchin, 1974; Sprenkle, Olson, & Russel, 2014). While enmeshed families are so involved in each other's affairs that they cannot function effectively as a family or as individuals, disengaged families do not seem to care much about each other (Segrin & Flora, 2011; Sprenkle et al., 2014).

3.6.2.8 Closedness or openness, input and output, and feedback loops.

Family systems take inputs and divert them to outputs; the type and degree thereof relate to the degree of closedness or openness of the system (Minuchin, 1974). A feedback loop is a path along which information can be traced from one point in a system, through one or more parts of the system or environment and back to the point where it originated. As an open system, a family receives information from the environment in the form of inputs and gives information back to the environment in the form of outputs (Broderick, 1993; Segrin & Flora, 2011). This process allows systems to sustain homeostasis or equilibrium through their adaptation to the environment (Broderick, 1993). This system can regulate its own behaviour as information entering the loop transforms and feeds back into the loop (Sprenkle et al., 2014). Negative feedback loops operate to maintain or restore equilibrium and play an important role in reaching and maintaining the stability of a system. One can view negative feedback when one or a few family members attempts to change (Minuchin, 1974). A positive feedback loop occurs when there is a deviation from homeostasis and this can relate to the potential for growth and development and not only deviation from homeostasis. Healthy families will counter positive feedback with negative feedback. Whereas closed families who cope with a childhood disability risk isolation, open families with permeable boundaries may feel overloaded with information. In childhood disability, closed boundaries tend to be more of a problem than open ones (Seligman & Darling, 2007).

3.6.2.9 Equilibrium.

Some level of tension is characteristic of and vital to systems. Families tend to use one of three types of strategies to maintain equilibrium: First, to preserve the relationship of parts as is; second, to highlight and accelerate the tension to push the family's relationships of parts into confusion; or third, to offer the family a chance to modify itself in order to remain a workable system (Becvar & Becvar, 2017; Goldenberg & Goldenberg, 2013).

3.6.2.10 Triangulation.

Triangulation is the tendency of a two-person emotional subsystem, which is under stress, to recruit a third person who acts as a go-between and disrupts partners or their chronic patterns of relation to each other (Goldenberg & Goldenberg, 2013).

3.6.2.11 Changing of needs and family life cycle, including disability.

Family needs change as the family life cycle continues. Furthermore, the goals and focus of the family are complex and shift frequently (Broderick, 1993; Miklowitz, 1994). Olson, Russel and Sprenkle (1983) identified seven stages of the family life cycle including adolescence. Each stage has its own developmental tasks and if a family has a child with impairments, it may result in challenges for family members if, for example, the parents resent remaining in a parental role and the youth with disabilities is unable to achieve independence (Seligman & Darling, 2007). The developmental stages derived from systems theory can be related to the stress that families of children with disabilities experience. According to Seligman and Darling, during adolescence, a family must cope with the chronicity of the child's disability, deal with sexuality issues, cope with peer rejection and isolation, and plan for the child's vocational future. Adolescence marks the period of separation from parents, searching for one's uniqueness and individuality and longing for peer acceptance; it is typically a stressful time of transition (Seligman & Darling, 2007).

Tasks that adolescents must accomplish include: establishing identity, achieving independence, adjusting to sexual maturation, preparing for the future, developing mature relationships with peers, and developing a positive body image and self-image (Seligman & Darling, 2007). When a chronic illness is first disclosed, a period of disequilibrium and adjustment follow for family members because they negotiate a complicated road to normalization and disequilibrium might function as a condition of stability (Luhmann, 2013; Seligman & Darling, 2007).

3.6.2.12 Process and structural characteristics.

Family systems possess both process and structural characteristics. Process characteristics include adaptability and permeability while structural characteristics include subsystems, hierarchy and boundaries (Wedemeyer & Grotevant, 1982).

3.6.2.13 Family interaction.

Patterns of family interaction, the key to family processes, can be an indicator of how families organize themselves to perform the activities that give them the characteristic of being enduring groups (Aldous, 1977).

3.6.2.14 Autonomy and intimacy.

In families, tension exists between autonomy and intimacy (Bion, 2003; Smith-Acuna, 2010). These extremes cause conflicts in families as members continually negotiate and clash when trying to find a balance (Olson, Russel, & Sprenkle, 2014).

3.6.2.15 Uncertainty and change.

Families experience challenges like uncertainty and change, which affect them and create conflict within their systems (Broderick, 1993; Minuchin, 1974). Families must then respond or adapt to daily and long-term developmental changes and challenges. This can sometimes cause families to become confused or shaken and dysfunctional (Fleming, 2003). Homeostasis occurs when the family re-stabilizes itself during times of change or uncertainty (Friedman, 1986).

3.6.3 Family Functioning and Change in Family Systems.

As members of a family develop and grow, their system must allow for change at different points in the family's life cycle. According to Becvar and Becvar (2014), in an evolving and growing family, there is a need for a shift in the balance between independence and dependence in the relationship between children and parents. When an adolescent has epilepsy, these normal shift changes might be challenged because the adolescent wants to be independent. However, because parents tend to be very involved in the management of the adolescent's epilepsy, certain levels of independence might not be reached when they normally would.

According to Becvar and Becvar (2014), two dimensions are involved in family functioning: cohesion, which is the degree of emotional bonding, enmeshed or disengaged; and adaptability, which is the ability of the family to balance stability and change, that is, morphostasis and morphogenesis, respectively. The most important aspect is a balance between enmeshment and disengagement, namely, cohesion and between stability and change, namely, adaptability. Effective communication is essential if a family is to develop the appropriate levels of bonding and adaptability necessary for optimal functioning.

3.6.4 Change in a Family System Related to Physical Illness.

Changes take place in family processes in the context of physical and emotional illnesses as the family operates as an interactive unit (Goldenberg & Goldenberg, 2013; Olson, 2002; Olson, Russel, & Sprenkle, 1983; Seligman & Darling, 2007; Vogt, Hofmann, & Getz, 2016). A diagnosis of epilepsy initiates changes in the family functioning. An example of second order change occurs when a family changes its type of system to adapt to the major stressor. Families with adolescents seem to have lower levels of wellbeing than families with younger children, even though they have similar levels of stressors and strains (Goldenberg & Goldenberg, 2013, Olson, Russel, & Sprenkle, 1983).

3.6.5 Family Systems Theory Perspectives on Epilepsy.

By helping a family to adjust to the illness of the adolescent member in their family, it is imperative to consider each member's reaction and behaviour (Carr, 2014; Goldenberg & Goldenberg, 2013). From the perspective of family systems theory, the researcher is of the opinion that an understanding of the family's experience requires a study of the family unit (Hauser, 1990). Studies of the family and chronic illness have tended to focus more on the family system, how relationships can predispose the already sick child to a more unstable clinical and vulnerable route, and/or how the child's course of illness can highlight disguised family problems (Hauser, 1990; Minuchin, 1974).

3.7 Family Functioning and a Systems View of Families

Families endeavour to create a functional system by trying to achieve a balance between extremes. A well-functioning set of relationships within a family will contain behaviour that represents both extremes (Becvar & Becvar, 2017). When a family experiences a challenge, it will function well if it has the capacity to shift or create a balance at an appropriate time within the context of the challenge (Becvar & Becvar, 2017). The McMaster model of family functioning (Epstein, Baldwin, & Bishop, 1983), which focuses on dimensions of functioning in a family, and the Circumplex Model of Olson, Russel and Sprenkle (1983, 2014) which focuses on family functioning through cohesion and adaptability, further describe family processes (Epstein, Baldwin, & Bishop, 1983; Epstein et al., 2003; Olson & Wilson, 1982). Two of the scales that formed part of the questionnaire that the participants completed originated from these models.

3.7.1 McMaster Model of Family Functioning (MMFF)

The McMaster model of family functioning (Epstein et al., 1983); Epstein, Ryan et al., 2003) builds on a systems approach by viewing a family as an integral whole (Becvar & Becvar, 2017; Epstein, Ryan et al., 2003; Ryan, Epstein, Keitner, Miller, & Bishop, 2012). It describes organizational and structural properties of the family group and patterns of transactions among family members to distinguish between unhealthy and healthy families. The model identifies six dimensions of family functioning; these are presented in Table 3.1.

Table 3.1

Dimensions of the McMaster Model of Family Functioning

Dimensions of family functioning	**Application of dimensions**
Problem solving	For a family to be able to *solve a problem* in an effective manner, it is important in a healthy functioning family that the stability of the family is not at risk because of unresolved problems
Communication	*Communication* is a guideline of family operations according to which one can transact the business of life by a family (Scherz, 1962).
Roles	*Family roles* refer to recurrent patterns of behaviour that family members display in order to fulfil family functions. Roles enable family members to deal with life changes by applying clear, flexible, age appropriate roles by members (Peterson & Green, 2009) and indicate a healthy functioning family.
Affective responsiveness	*Affective responsiveness* in families implies the ability to respond in an emotionally appropriate way to other members of the family (Epstein et al., 2003). Families who are not in a position to express or display feelings can become emotionally distanced and restricted whereas healthy functioning families can experience and share feelings (Peterson & Green, 2009).
Affective involvement	*Affective involvement* refers to the interest in activities of other family members. Balance plays an important role, as under-involvement and over-involvement can be a problem for members of a family (Epstein et al., 2003; Peterson & Green, 2009).
Behaviour control	*Behaviour control* includes the patterns of behaviour that families use to help them to deal with family situations (Epstein et al., 2003). Flexible behaviour patterns help families to cope better with changing circumstances (Peterson & Green, 2009).

3.7.2 Circumplex Model of Marital and Family Systems

Olson et al. (1983) developed the Circumplex model, which involves two dimensions of family functioning, namely, adaptability and cohesion (Becvar & Becvar, 2017; Olson, 2002; Olson & Wilson, 1982). Adaptability is the ability of the family to balance stability, that is, morphostasis, and change, namely, morphogenesis. Cohesion is the degree of emotional bonding. According to Minuchin (1974), it is important to create a balance between enmeshment and disengagement, namely, cohesion and between stability and change, which is adaptability. Families may be classified in four categories on the cohesion and adaptability dimensions, from lowest to highest:

1. Cohesion: Disengaged, separated, connected and enmeshed; and
2. Adaptability: Rigid, structured, flexible and chaotic.

The facilitating dimension of the Circumplex model is family communication, which is essential if a family wants to develop appropriate levels of bonding. Adaptability is necessary for optimal functioning (Becvar & Becvar, 2014). There are 16 categories that emerge from the Circumplex model.

These are depicted in Figure 3.1.

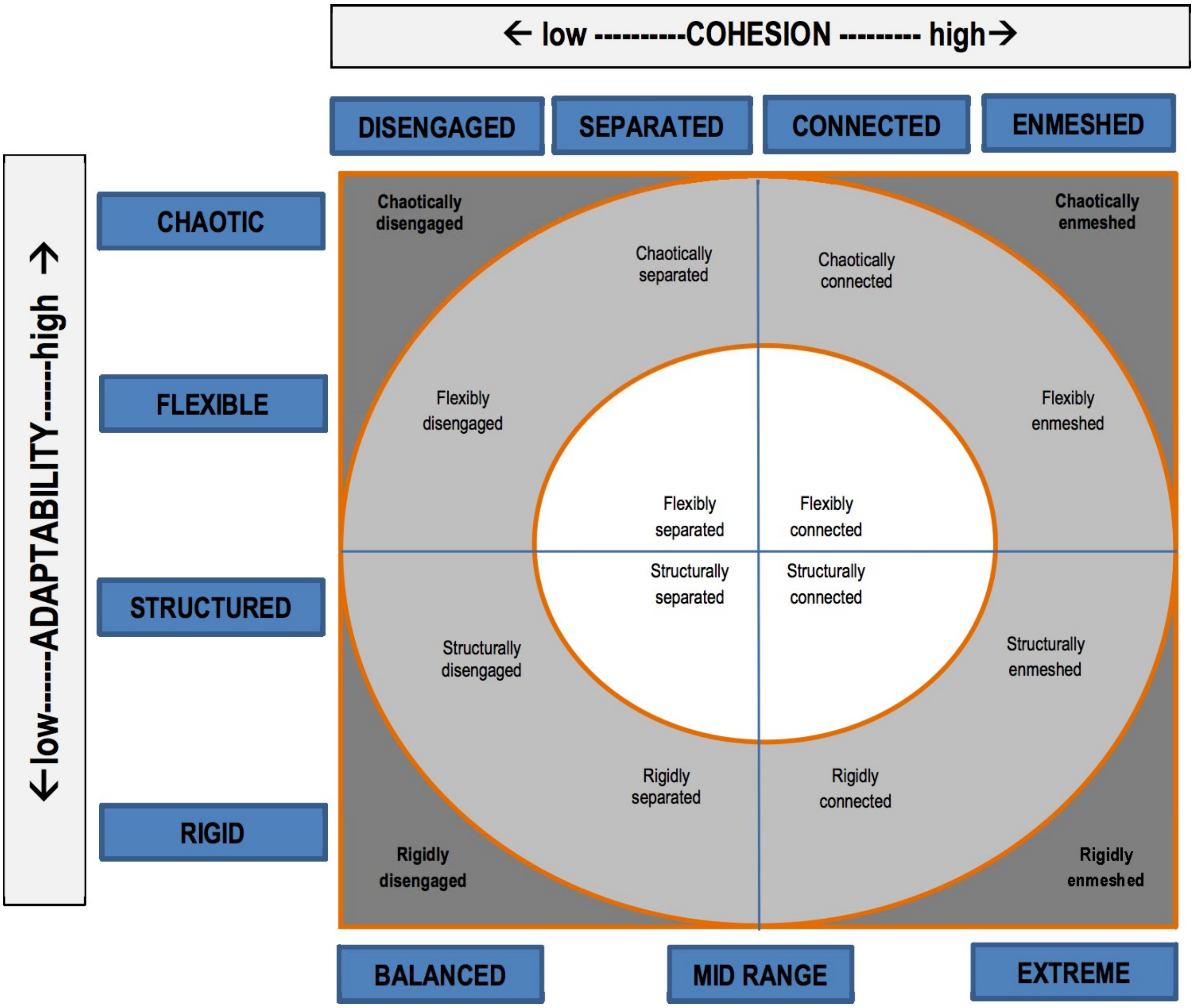


Figure 3.1. The Circumplex model (Olson, 2012)

3.7.2.1 Family cohesion (togetherness).

Family cohesion refers to the emotional bonding that family members have toward each other. The variables used to measure this include *emotional bonding*, *boundaries*, *coalitions*, *time*, *space*, *friends*, *decision-making, and interests* and *recreation* (Olson et al., 1983). There are four levels of cohesion, which range from *disengaged* (very low) to *separated* (low to moderate) to *connected* (moderate to high) to *enmeshed* (very high). It appears that the central levels of cohesion, that is, separated and connected, measure optimal family functioning (Carver & Jones, 1992; Olson, 2012; Olson et al., 1983). The extremes, namely, disengaged and enmeshed are problematic. In the ‘balanced’ area of the model, that is, separated and connected, individuals are able to *experience and balance* these two extremes, and can be both independent from and connected to their families. When cohesion levels are very high, that is, they are enmeshed, there may be too much consensus and too little independence within the family. At the other extreme, namely, disengaged, family members tend to have limited commitment or attachment to their family and do their own thing (Olson et al., 1983). Balanced couple and family systems, separated and connected types tend to be more functional (Olson, 2002; Olson et al., 1983). Although a *separated* relationship may have a degree of emotional separateness, it is not as extreme as the disengaged system. In a relationship like this, time apart is very important, even though they may spend some time together, enjoy some mutual support and take joint decisions. They may share a few interests and activities, even though they generally do not engage in these together. A *connected relationship* has emotional closeness in which there is loyalty to the relationship. Time together is more important than time apart and the focus falls on togetherness. Although the marital couple have separate friends, they share some friendships. Furthermore, even though they share interests, they also engage in separate activities (Olson, 2002; Olson et al., 1983).

Unbalanced levels of cohesion may be extreme when they are either very high or very low. A *disengaged relationship* is often characterized by extreme emotional separateness and much personal independence and separateness (Olson, 2002; Olson et al., 1983). There is little involvement among family members and members are unable to turn to one another for support and problem-solving. Individuals often do their own thing, and have separate interests, space and time. In an *enmeshed relationship,* there is a lot of emotional closeness. Furthermore, it demands loyalty, and individuals may be very dependent and reactive to one another. They permit each other little private space and there is a lack of personal separateness. The individuals focus mainly inside the marriage or family and they enjoy few outside individual interests and friends. Olson (2002) and Olson et al. (1983) explained that very high and very low levels of cohesion, enmeshment and disengagement, may be problematic for the development of individuals and relationships. Relationships with moderate, connected and separated scores, can balance being alone versus being together in a more functional way. It appears as though some relationships may be problematic if they always function at either extreme of the Circumplex model, disengaged and enmeshed, for too long.

3.7.2.2 Marital and family flexibility.

In this section, the views of Olson (2002) and Olson et al. (1983) in relation to marital and family flexibility are discussed. They expressed the opinion that *family flexibility* is defined by the amount of change in leadership, role relationships and relationship rules. There are four levels of flexibility, which range from *rigid* (very low) to *structured* (low to moderate) to *flexible* (moderate to high) to *chaotic* (very high). Central levels of flexibility, that is, flexible and structured are more conducive to marital and family functioning whereas the extremes, that is, rigid and chaotic are the most problematic for families as they move through the family life cycle (Olson et al., 1983). Couples and families need both stability and change, which involves the ability to change to be functional (Olson, 2012). Over time, balanced couple and family systems, the structured and flexible types, tend to be more functional. Democratic leadership may include various negotiations as well as the children and a structured relationship. There are few rule changes and the rules are firmly enforced in these families (Olson, 2012). A flexible relationship has an equalitarian leadership and a democratic approach to decision-making. Negotiations in such a family are open and actively involve the children. Family members share roles and there is fluid change when necessary. Family members may change the rules, which are age-appropriate (Olson, 2002).

Chaotic or rigid families tend to have unbalanced marriages. When one individual is in charge and is highly controlling, a rigid relationship exists. There are limited negotiations and most decisions are imposed by the leader. Strictly defined roles of family members are applicable with no changing of rules. A chaotic relationship has an erratic or limited leadership (Olson, 2012). Decisions are impulsive and not well thought out. Roles are unclear and often change from individual to individual. Very high levels of flexibility and very low levels of flexibility, that is, chaotic and rigid, respectively, can ultimately be problematic for individuals and relationship development. On the other hand, relationships with moderate scores, that are structured and flexible are able to balance some change and stability in a more functional way. Many relationships may experience problems if they always function at either extreme, rigid or chaotic, of the model for an extended period.

3.7.2.3 Marital and family communication.

Marital and family communication is referred to as a facilitating dimension because in order to advance cohesion and flexibility, communication is imperative. According to Olson (2002) and Olson et al. (1983), communication is not graphically included in the model with cohesion and flexibility because it is a facilitating dimension. One can measure family communication by focusing on the family as a group and paying attention to their listening skills, speaking skills, self-disclosure, clarity, continuity tracking, respect and regard. In relation to listening skills, the focus is on empathy and attentive listening. Speaking skills include speaking for oneself and not speaking for others. Self-disclosure relates to sharing feelings about self and the relationship. This includes staying on the topic, showing respect and relating to the affective aspects of the communication. Several studies, which have investigated communication and problem-solving skills in couples and families, have found that balanced systems tend to have good communication, while poor systems tend to be characterized by poor communication (Olson, 2002).

3.7.2.4 Three-dimensional Circumplex model: First- and second-order change.

According to Olson (2002) and Olson et al. (1983), first-order change may occur in a given family system. It represents a ‘change in degree’ in that the basic family system does not change. The flexibility dimension represents first-order change. Second-order change is when one system type changes to another type of system. It is a ‘change of the system itself’ and the assessment thereof takes place over time. In addition, under stress these patterns become more apparent. Second-order change can occur in times of normative stress such as the birth of a child, or non-normative change, for example, when a parent sustains an injury in a car accident or has a chronic illness (Olson, 2002; Olson et al., 1983).

3.7.2.5 Hypotheses derived from the Circumplex model.

A hypothesis of the Circumplex model is that balanced types of families, in comparison to extreme types of families, will do better because they are able to change their family system in order to cope more effectively with the illness in a family member. Families with balanced types, that is, the two central levels of cohesion and flexibility will generally function more adequately across the family life cycle than those in unbalanced or extreme types (Olson, 2002; Olson et al., 1983). Family systems need to balance their separateness versus togetherness on cohesion and their level of stability versus change of flexibility (Olson, 2012). Being balanced means that a family system can experience the extremes on the dimension when appropriate even though it does not typically function at these extremes for long periods. Families in the balanced area of the cohesion dimension allow family members to experience being independent from as well as connected to their family. In relation to flexibility, balance means maintaining some level of stability in a system with openness to some change when it is necessary. Extreme behaviour on these two dimensions can be appropriate for certain life cycle stages including when a family is under stress. It can be problematic when families are stuck at the extremes. Extreme types of family systems are not necessarily dysfunctional, especially if a family is under stress. If a family’s expectations support more extreme patterns, families will then operate in a functional manner as long as all the family members desire the family to be that way (Olson, 2002; Olson et al., 1983). Positive communication skills will enable balanced types of families to change their levels of cohesion and flexibility more easily than unbalanced or extreme types.

Families will modify their cohesion and adaptability to deal with situational stress and developmental changes across the family life cycle (Olson, 2002; Olson et al., 1983). The hypothesis is that families will deal with stress or accommodate changes in family members, particularly when family members change their expectations. Family systems will change in response to a crisis. According to the Circumplex model, the balanced families will have the skills and resources to shift their system to cope more effectively with a crisis (Olson, 2002; Olson et al., 1983). On the other hand, it seems that extreme families may not have the resources that are necessary to change and they may find it more difficult to adapt to a crisis. Balanced families can adjust their family system better to adapt to a family crisis (Olson, 2002; Olson et al., 1983).

The Circumplex model is dynamic in that it assumes that families will change type. It hypothesizes that change may be beneficial to the maintenance and improvement of family functioning. When one family member desires change, the family system must somehow deal with that request. Adolescents often want more freedom, independence and power in the family system. These pressures to change the family system by one member canfacilitate change in the family, which often tends to resist any change (Olson, 2002; Olson et al., 1983).

3.8 Conclusion

When examining families systemically, different processes are visible in relation to coping and functioning. Family systems theory from a position of critical realism explains how families might experience living with an adolescent diagnosed with epilepsy and the family processes reported by the patient and family members. In Chapter 4, the research methodology and collection of quantitative and qualitative data are detailed.

CHAPTER 4: METHODOLOGY

In this study, the family processes related to family satisfaction, family functioning and hardiness of families with an adolescent with a diagnosis of epilepsy were explored. A mixed methods approach was employed. In this chapter, the aim and objectives, research design and research methods of the study are detailed.

4.1 Research Questions

- **Quantitative Research Questions**

The quantitative research questions that directed this study were two-fold. First, what were the family process profiles, namely, the family satisfaction, family functioning and hardiness reported by the patient and family members? Second, what were the differences between patient and family members' family process profiles, that is, family satisfaction, family functioning and hardiness?

- **Qualitative Research Questions**

The qualitative research questions that directed the study were also two-fold. First, what is the experience of families living with an adolescent diagnosed with epilepsy? Second, according to the patient and family members, what is the impact of epilepsy on the family processes and functioning?

- **Mixed Methods Research Question**

The mixed methods research question was: To what extent and in what ways do the quantitative data from adolescent epilepsy patients and family members concur with the qualitative results?

4.2 Philosophical Worldview: Critical Realism

As noted in Chapter 3, the paradigmatic point of departure in this study was family systems theory and its application from a position of critical realism. The aim, through critical realism, was to describe an objective reality by examining families from the *outside* while conceding that although it is not possible to be completely objective, it is approachable (Allana & Clark, 2018; Bhaskar, 2013; Bhaskar, Esbjörn-Hargens, Hedlund, & Hartwig, 2015; Cruickshank, 2012; Fletcher, 2017; Pocock, 2015; Wagner, Kawulich, & Garner, 2012; Walsh & Evans, 2014; Willig, 2013). Critical realism may be viewed as an integration of a realist ontology in which there is given recognition of a real world that exists independently of our constructions, theories and perceptions in conjunction with a constructivist epistemology that resembles our understanding of the world (Bhaskar, 2013; Creswell & Clark, 2017; Pocock, 2015).

The critical realist perspective is a valuable contribution to mixed methods research as it supports and validates important aspects of both qualitative and quantitative approaches (Creswell & Clark, 2017; Zachariadis et al., 2013). It creates a way to avoid attempting to decide between the contributions of extreme relativism and extreme realism (Forrester & Sullivan, 2018). Critical realism recognises that the subjective element in knowledge is necessarily contextual and standpoint dependent; thus, different insights can be applied to the same phenomenon from different perspectives. Accuracy of representations is thus not as important as being concerned with completeness in the research (Willig, 2013).

Forrester and Sullivan (2018) described the following common features of critical realism:

- Knowledge is culturally and historically specific. Research is a social process where values form part of the context and consequently, research methods can never be truly objective. In this study, the researcher tried to be sensitive to experiences and treated the participants with respect in relation to how they viewed their experience within their culture.
- Although imperfect, access to a reality beyond discourse is possible. This is reflected when the researcher adopted a meta-perspective on what was said in an effort to acquire an enhanced understanding of what the participants conveyed as part of their experience.
- Our culture, power and perspectives will always distort our knowledge of reality to some extent. For example, in this study, the diagnosis of epilepsy already influenced the participants' perspectives. Whereas in some cultures, those with epilepsy believe it is a medical condition, in other cultures and religious viewpoints, those with the illness perceive it to be a curse.
- The evaluation of truth may be contrary to evidence found. Social construction of truth exists to some extent. The participants of this study might have evaluated their truth of their experience against their current knowledge of epilepsy.

4.3 Aim and Objectives

The purpose of the study was to explore family processes in families with adolescents diagnosed with epilepsy. The specific objectives were to: Explore family processes from the perspective of the patient and family members; and, describe family processes in terms of satisfaction, family functioning and hardiness.

4.4 Research Design

Mixed methods research designs involve a combination of quantitative and qualitative methods, approaches, research techniques and concepts in the same study (Creswell, 2014, 2015; Johnson & Onwuegbuzie, 2004; Onwuegbuzie & Leech, 2005). In this study, the researcher employed a mixed methods approach with a triangulation design and a convergence model to triangulate quantitative and qualitative data for the broad purpose of depth of understanding, breadth and corroboration (Choi, 2015; Creswell, 2014, 2015; Creswell & Clark, 2017; Curry & Nunez-Smith, 2014; Willig, 2013). The researcher compiled one questionnaire for the family members and adolescent patients to complete. It comprised socio-demographic information and four scales (refer to Table 4.1 below) that the researcher selected for the study. Although the family members completed the same questionnaire as the patients, the family members were required to provide more detail in the biographical section as the researcher assumed that this information would be more accessible to the family members than the patients. The family questionnaire and patient questionnaire are attached as Attachments A and B. The contents of the questionnaire are presented in Table 4.1.

Table 4.1

Contents of the Questionnaire

The Questionnaire	
Questionnaire for patients	**Questionnaire for family members**
Socio-demographical information	*Socio-demographical information (same information requested from the patient plus more information about the family members and epilepsy diagnosis)*
Family Satisfaction Scale (FSS) (Olson & Wilson, 1982)	FSS
Family Functioning Scale (FFS) (Dunst, Trivette, & Deal, 1988)	FFS
Family Hardiness Index (FHI) (McCubbin, McCubbin, & Thompson, 1991)	FHI
Family Assessment Device (FAD) (Epstein, Baldwin, & Bishop, 1983)	FAD

The qualitative data was obtained by conducting semi-structured interviews and administering the Graphic Family Sculpting technique (GFS) with the participating family members (Lewis, 2015). The quantitative and qualitative data were collected simultaneously (Collins, Onwuegbuzie, & Jiao, 2006; Creswell, 2014, 2015; Curry & Nunez-Smith, 2014). Furthermore, typically, the data collection process started with the family interview; this was followed by administering the GFS and finally, completing the questionnaires.

4.5 Rationale for Using Mixed Methods Research

Health sciences researchers require capacity to measure multifaceted phenomena, are solution-focused and want to generate practical and theoretical knowledge for the public as well as for professional groups. Mixed methods approaches have the potential to advance research in health sciences (Curry & Nunez-Smith, 2014; Wittink, Barg, & Gallo, 2006). Mixed method approaches are often employed in health psychology and medically-related research where readers desire objectivity, numbers and generalizability, and where the researcher wants to support the findings with a rich description of experience from the patients' perspectives (Bergman, 2010; Choi, 2015; Curry & Nunez-Smith, 2014; Frost, 2011; Halcomb & Hickman, 2015; Todd, Nerlich, McKeown, & Clarke, 2004). Quantitative and qualitative methods of data collection provide different types of information. By combining the strengths of both, the researcher endeavoured to develop a more enhanced and deeper understanding of the research problem. Furthermore, the limitations of both qualitative and quantitative methods were minimised, and the quantitative findings were enriched by the qualitative findings (Bowen, 1976; Brink, Van der Walt, & Van Rensburg, 2006; Collins et al., 2006; Creswell, 2014; Creswell & Clark, 2017; Imran & Yusoff, 2015; Santos et al., 2017; Zhang & Creswell, 2013).

A disadvantage of mixed methods research is that the sample may be small. However, although findings cannot directly be generalized such as in larger representative and/or random samples (Creswell, 2014; Polit & Beck, 2004), it sheds light on what these families may experience and which areas need further research. Thus, the qualitative aspect allows one to consider the situational context and hear the voices of the participants (Creswell, 2014; Creswell & Clark, 2017). Mixed methods research provides more comprehensive evidence for studying a research problem and helps one to obtain different, but complementary data on the same topic (Castro, Kellison, Boyd, & Kopak, 2010; Creswell, 2014, 2015; Creswell & Clark, 2017; Denzin & Lincoln, 2011; Santos et al., 2017).

4.6 Triangulation Design: Convergence Model

The researcher employed a triangulation design in conjunction with the convergence model to obtain different, but complementary data to answer the same research question (Creswell, 2014, 2015; Creswell & Clark, 2017; Curry & Nunez-Smith, 2014; Halcomb & Hickman, 2015; Santos et al., 2017). The purpose of this study was to collect both quantitative and qualitative data concurrently, analyse both datasets separately, finally merge the two sets of data analyses, compare the results and integrate them during the interpretation thereof (Creswell, 2015; Halcomb & Hickman, 2015; Willig, 2013; Zhang &

Creswell, 2013). Quantitative and qualitative data were afforded the same importance in this study.

In Table 4.2, the steps and decisions that the researcher took in this mixed methods data analysis by employing a convergence model are explained.

Table 4.2

Steps and Decisions in Mixed Methods Data Analysis by Convergence Model

Type of methods data analysis	**Data analysis steps in the design**	**Data analysis decisions**
Merged data analysis to compare results	• Collected quantitative and qualitative data concurrently • Independently analysed the quantitative data and the qualitative data using analytic approaches best suited to the quantitative and qualitative research questions • Specification of the dimensions by which to compare the results from the two databases • Specification of information that would be compared across the dimensions • Completion of refined quantitative and/or qualitative analyses to produce the needed information for comparison • Representation of the comparisons • Interpretation of how the combined results answer the quantitative, qualitative, and mixed methods questions	Decided how the two data sets would be compared (e.g. dimensions, information)

In Figure 4.1, the process in which both forms of data were collected simultaneously and had equal emphasis, and the results of the converged data are depicted (Creswell, 2014, 2015; Curry & Nunez-Smith, 2014; Santos et al., 2017).

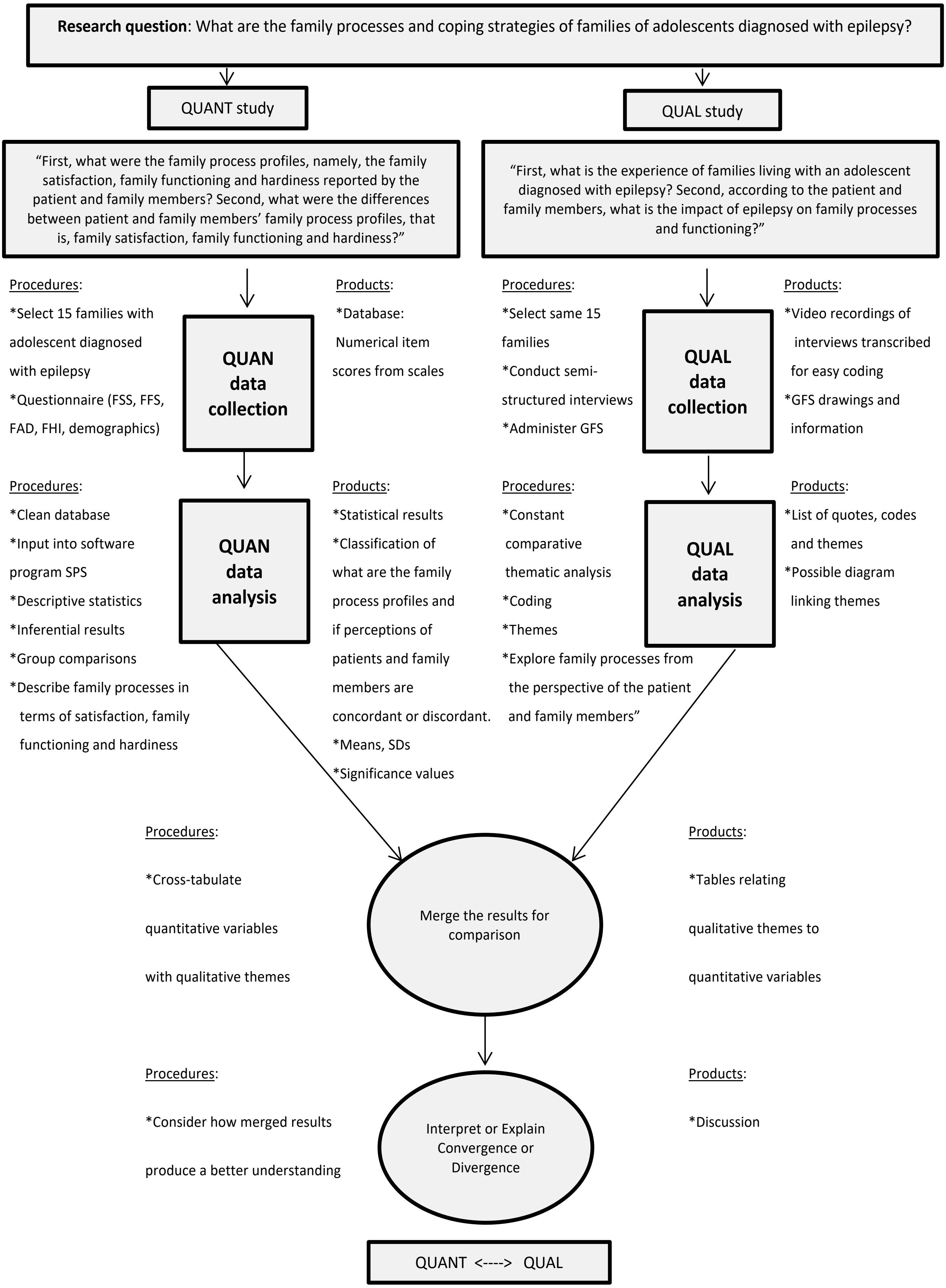


Figure 4.1. Convergent design used in the study

4.7 Procedure

In this section, the procedure, in particular, the sampling method, selection criteria for participants, data collection strategies and data analysis used in the study are detailed.

4.7.1 Sampling

The researcher employed purposeful sampling, which by virtue of its accessibility was available (Becker, Bryman, & Ferguson, 2012; Collins et al., 2006; Neuman, 2014). The sample consisted of 15 adolescent patients diagnosed with epilepsy and their families. Fifteen adolescents with epilepsy and their families were recruited during April 2014 to April 2015. Neurologists practicing at private hospitals made referrals of patients for the research on the basis of the selection criteria provided to the neurologists by the researcher. Prior to the interview the researcher telephonically contacted the families to discuss the purpose of the research, issues of risk and anonymity and freedom to withdraw. Participants received a copy of the research information leaflet before the interview were arranged and had the opportunity to ask any questions and have these answered.

The researcher balanced the demands of different criteria in the final choice of 15 families to achieve scientific rigour. It was important to select as large a sample as possible for the quantitative part of the study to minimize errors on how well the sample reflected the characteristics of the population. However, for the qualitative part, it was imperative for the focus to be on a purposeful selection of participants who could best assist an understanding of the main phenomenon explored in the study (Creswell, 2014, 2015). This provided data to ensure a rich description (Creswell, 2015). The researcher interviewed selected participants who completed a questionnaire and the GFS at least six months after an initial diagnosis of epilepsy. This temporal gap ensured that the patients had a confirmed diagnosis of epilepsy and their condition had been stabilized with medication.

When conducting mixed methods research with a convergent design, it is ideal for the participants to be from the same population (Creswell, 2015). Consequently, neurologists at private hospitals made referrals of patients for the research. The cost of convenience sampling is low and access is quick in comparison with other types of sampling. However, findings, in relation to the nature of the sampling, more specifically, the small size and convenience thereof, cannot be generalized.

Initially, the neurologists that the researcher approached, when forming ideas in relation to the type of research she wanted to conduct, were all keen to participate and referred some of their patients. These neurologists expressed the opinion that the research could add value to the service that they deliver to their patients. Discussions the researcher held with neurologists in private practice helped her to identify a need and gap in the fields of neurology and psychology, especially in relation to support for adolescent patients diagnosed with epilepsy. The neurologists asked patients and family members whom they were treating whether they would be willing to participate in the study. Accordingly, the neurologists provided contact details of this initial selection of patients to the researcher so that she could make further arrangements with the patients and their families to participate in the study. Information leaflets (Appendix C) compiled by the researcher were made available to patients and family members at the consultation rooms of the neurologists. Furthermore, the researcher sent each participating family a leaflet with information after initial contact via e-mail.

4.7.2 Selection Criteria for Participating Patients and Family Members

The participants had to meet the following criteria:

- The participants could be from any ethnic group and gender.
- The participants had to be proficient in English or Afrikaans.
- The patients had to be between the ages of 13 and 18 at the time of participation.
- The patients had to have a confirmed diagnosis of epilepsy and their condition had to be stabilized as a result of medication.
- The participating family members had to be members of the patient's family, and either living with the adolescent in the same household or involved in the adolescent's life.
- More than one member of each family was encouraged to participate. The researcher was able to elicit rich descriptions of family processes in this manner.

4.7.3 Data Collection Strategies

Quantitative and qualitative data were collected in a three-fold process during the same session with each family. The strategy is summarized in Table 4.3.

Table 4.3

Data Collection Process

Quantitative	**Qualitative**	
Questionnaire consisting of:	Interviews:	
- Biographical information - Family Satisfaction Scale (FSS) - Family Functioning Scale (FFS) - Family Hardiness Index (FHI) - Family Assessment Device (FAD)	- Semi-structured - With the adolescent patient diagnosed with epilepsy and family members - Facilitated by the researcher	GFS: - By all participants (patients and family members)
Questionnaire completed by:		
- The adolescent patient diagnosed with epilepsy who participated in the research - The family members who participated in the research		
Focus on:		
- What are the family process profiles reported by the patient and family members - What are the differences between patient and family members' profiles	- Focus on how families experience living with an adolescent diagnosed with epilepsy, and the impact of epilepsy on the family processes and functioning according to the patient and family members	- Focus on how families experience living with an adolescent diagnosed with epilepsy, and the impact of epilepsy on the family processes and functioning according to the patient and family members

The researcher conducted interviews between 17 April 2015 and 21 April 2016. Data collection either took place when the patient had a follow-up neurology consultation or as a separate scheduled appointment with the researcher. Data collection occurred at offices in close proximity to the particular neurologist's consulting rooms. These offices were session consulting rooms that the three participating neurologists and a psychologist colleague use, and made available for the purpose of the research. However, three of the interviews were conducted in the homes of the particular patients. The researcher was present when participants asked questions about the questionnaires. Because the researcher wanted more information on the perceptions of the patients and their family members, the patients were requested to complete a separate GFS and questionnaire without consulting their family members. Where only the patient and a family member were present, they sat in the same room while completing the GFS and questionnaire on their own. However, in instances where more family members were present, either the patient or family members moved to another room where each party could complete the GFS and questionnaire in private. A representative of each family completed the questionnaire, after involving the input of and discussion with the other family members as well as their answers to the questions in the questionnaire.

The collection of qualitative data, that is, interviews and GFS with each family took between one and two hours, and the collection of the quantitative data took approximately 30 to 45 minutes. The data collection started with a pilot study on 17 and 21 April 2014, and continued with the rest of the data collection, which was completed on 21 April 2016. After the completion and review of the pilot study, the researcher found that the data from the pilot study interviews were relevant and appropriate. Consequently, these data were included in the data of the study.

4.8 Quantitative Data Collection

The participants completed a biographical questionnaire, the Family Satisfaction Scale (FSS) (Olson & Wilson, 1982), the Family Functioning Scale (FFS) (Dunst, Trivette, & Deal, 1988), the Family Hardiness Index (FHI) (McCubbin, McCubbin, & Thompson, 1991) and the Family Assessment Device (FAD) (Epstein, Baldwin, & Bishop, 1983), (refer to Attachments A and B). The researcher was aware that the family values and dynamics, on which these theoretical constructs are based, may have differed in the contexts of the participants in this study. However, several South African studies have reported psychometric information on the standardized assessments that were employed in this study (Botha, Van den Berg, & Venter, 2009; Brown, Fouche, & Coetzee; 2010; Greeff, Vansteenwegen, & Geldhof, 2014; Koen, 2009, 2012; Pillay & Wassenaar, 1997; Roux, 1997).

The researcher's choice of measuring instruments was influenced by family systems theory. The researcher based her choice on the definition of family processes and the functioning of families, and measured the constructs with specific instruments. Furthermore, the researcher assumed that the family represents an integral whole that is more than the sum of its lower order features (Minuchin, 1974). Moreover, the researcher's choice originated from a family system perspective, which postulates that the patient and family members are part of a complex integrated system (Staccini, Tomba, Grandi, & Keitner, 2015). The researcher wanted input from multiple family members who could provide assessments of the characteristics of the family. Questionnaire items that targeted the family as a whole, which correlated with how systems theories view the family (Georgiades, Boyle, Jenkins, Sanford, & Lipman, 2008), assisted in this goal by examining whether family members were satisfied with family life, family functioning, and hardiness. The main measurement constructs of the scales are presented in Table 4.4.

Table 4.4

Main Measurement Constructs of the Different Scales

Measuring Instruments	Main constructs measured
Biographical information	Biographical information of patient and family
FSS	Family satisfaction, measured in terms of subscales on cohesion (or togetherness) and adaptability (or flexibility) of the family.
FFS	Measures positive aspects of family functioning or strengths.
FHI	Measures hardiness in family adjustment and adaptation over time.
FAD	Assesses whole family functioning according to multiple family members' perceptions.

4.8.1 Biographical Information Scale

The researcher compiled a biographical questionnaire, which was included in the participants' questionnaire (part of Appendix A). The biographical questionnaire was employed to obtain socio-demographic information such as the age, highest educational qualification, gender and ethnic group of the participants and their families. The patients and their families completed questionnaires; however, they were required to answer different questions in relation to the biographical information of the patient and family. In accordance with the researcher's clinical experience in practice and previous research conducted, which was reviewed in Chapter 2, the researcher included specific questions in the biographical questionnaire to obtain information to ascertain whether certain variables (as set out in Appendix A) play a possible role in the family processes and the functioning of these families. The literature highlights that the influence of socioeconomic status, and family structure and composition can play a possible role in the processes and functioning of families (Georgiades et al., 2008).

4.8.2 The Family Satisfaction Scale (FSS) (Olson & Wilson, 1982.)

Family satisfaction refers to "the degree to which one is generally satisfied with one's family of origin and the constituent relationships imbedded therein, for example, parent-child, and sibling relationships," (Carver & Jones, 1992, p. 72) as well as the degree to which family members feel fulfilled and happy with each other (Olson, 2010). The FFS indicates how attitudes and feelings about one's family feature in dysfunctional and normal families. Indices of validity (refer to 4.17) and internal reliability meet acceptable standards of measurement and the scale correlates in appropriate and meaningful ways with other family assessment measures (Carver & Jones, 1992).

The FSS (attached as part of Appendix A) focuses on the dimensions of family cohesion, adaptability and communication; this is presented in Table 4.5. The FSS was developed from the Circumplex model as explained in Chapter 3 (Olson, 2002, 2010; Olson & Wilson, 1982; Walsh, 2012).

Table 4.5

Family Satisfaction Assessed on the Dimensions of Family Cohesion, Adaptability and Communication

Family Satisfaction Scale		
Family cohesion/togetherness	**Adaptability/flexibility**	**Communication**
Degree of emotional bonding - creates a sense of unity, steers a family's interactions	How the family adapts and meets change and demands.	A facilitating dimension - communication is critical for families to alter their levels of cohesion and flexibility.

When applied to the research question and systems theory, it was assumed that if there was good communication in a family, it may function better as a system. Furthermore, it may provide more information and insight on the family processes.

The scale consists of 14 items, which are assessed on a five-point Likert-type scale: 1 = dissatisfied, 2 = somewhat dissatisfied, 3 = generally satisfied, 4 = very satisfied and 5 = extremely satisfied (Neuman, 2014). The reliability of the original 14-point scale assessed by Cronbach's alpha is 0.94 (12 months, N = 541) and 0.95 (60 months, N = 340) and the five-week test-retest correlation for the total score of the scale is 0.75 (Olson & Wilson, 1982). The test-retest Pearson correlation (n = 106) on the total score is 0.75 and Cronbach's Alpha (n = 2076) on the total score is 0.92 (Olson & Wilson, 1982).

The primary hypothesis postulated that *balanced* families generally function more adequately than *extreme* families and that *balanced* families are more satisfied with their system than *unbalanced* families (Olson, 2010; Olson & Gorall, 2003; Olson & Wilson, 1982; Walsh, 2012). A detailed description of application of the Circumplex model can be found in Chapter 3. Families with high scores on balanced cohesion and flexibility have higher levels of family satisfaction. Families with high scores on unbalanced scales have lower levels of family satisfaction. Balanced families have significantly higher family satisfaction than unbalanced families (Olson, 2010). Family satisfaction is positively related to family communication. Families who experience high family satisfaction have significantly better family communication than families who experience low family satisfaction (Olson, 2010).

The FSS is available in the original 14-item scale and the revised 10-item scale; both are designed to assess satisfaction with various aspects of family functioning including family closeness, flexibility and communication (Olson, 2010). The original 14-item scale was used in this study because it has a wider variety of questions to use for observations in relation to family processes and family functioning as part of the research question. The FSS has been widely used in family research and as an assessment of family satisfaction (Carver & Jones, 1992; Cashwell & Vacc, 1996). Previous South African research on adolescents has employed this scale (Koen, 2009, 2012; Pillay & Wassenaar, 1997; Roux, 1997). The researcher requested and obtained permission to use this scale from the authors (Appendix D).

4.8.3 The Family Functioning Scale (FFS), (Dunst, Trivette, & Deal, 1988)

The FFS (attached as part of Appendix A) is a family-centred assessment that specifically measures the positive aspects of family functioning or family strengths (Dunst et al., 1988; Early, 2001; Trivette, Dunst, Deal, Hamer, & Propst, 1990). Family functioning refers to the ability of the family to work together as a unit to satisfy the basic needs of its members (Ryan & Keitner, 2009). The FFS is a self-report measure, which includes 26 statements that can be completed by the family as a unit or by an individual family member; they are required to assess the degree to which each statement is characteristic of their family (Dunst et al., 1988). The scale items are rated on a five-point Likert scale, ranging from not at all like my family (0) to almost always like my family (4). The range of the total score is from 26-130. Higher scores indicate family strengths and sound family functioning (Trivette et al., 1990). There are two separate coping style subscales (Dunst et al., 1988). The FFS covers three domains: Family identity, information sharing and coping or resource mobilisation. The FFS is widely used in research (Koen, 2012), and although its use has been limited in South Africa, the researcher chose to use it as the items appeared to be generic. Higher scores are indicative of family strengths and sound family functioning (Trivette et al., 1990).

This scale has a split-half reliability coefficient of 0.85 and the average correlation among the items is 0.92 (Dunst et al., 1988). The researcher requested and received permission from Winterberry Press to use the scale (Appendix E).

4.8.4 The Family Hardiness Index (FHI) (McCubbin, McCubbin & Thompson, 1991)

The FHI measures the durability and internal strengths of the family unit (McCubbin et al., 1991). Family hardiness focuses on a family's patterned approach to life's hardships. This typical pattern of appraising the impact of life events and changes on family functioning is a comment on a family's co-oriented commitment to manage difficulties and its confidence in being able to handle problems (McCubbin, McCubbin, & Thompson, 1986).

The FHI consists of 20 items, which respondents assess on a four-point Likert-type scale. The FHI has four subscales: Co-oriented Commitment, Confidence, Challenge, and Control, which reflect a *we* rather than an *I* orientation. The respondent must assess the degree to which each statement describes their current family situation; the options include false, mostly false, mostly true, true. The higher the score on the FHI, the higher the hardiness of the family. The scale has a Cronbach's alpha of 0.82 and high internal reliability (McCubbin et al., 1991).

The FHI is used in South Africa and internationally, and is currently in the public domain. It forms part of Appendix A (Baez, 2000; Brown, Fouche, & Coetzee, 2010; Greeff et al., 2014; Koen, 2012; McCubbin et al., 1991; Robinson, 2003).

4.8.5 The McMaster Family Assessment Device (FAD) (Epstein, Baldwin & Bishop, 1983)

The sudden occurrence of an illness in a previously healthy family may irrevocably change the family's functioning (Staccini et al., 2015). The FAD is a self-report measure, designed to assess whole family functioning according to multiple family members' perceptions. It was developed from the McMaster Model of Family Functioning (MMFF), which was described in Chapter 3 (Epstein et al., 1983; Georgiades et al., 2008). The FAD collects information on the six dimensions of the McMaster Model of family functioning: Problem-solving, communication, roles, affective responsiveness, affective involvement, behaviour control and general functioning (Boterhoven de Haan, Hafekost, Lawrence, Sawyer, & Zubrick, 2015; Byles, Byrne, Boyle, & Offord, 1988). This related well to the systems theory that the researcher employed as part of the approach. The aim was to collect this information directly from family members so as to acquire an enhanced insight in their different viewpoints (Epstein et al., 1983). The FAD continues to be one of the most widely used measures of family functioning. It is a relevant and useful tool to assess family functioning in both clinical and research contexts (Bihun, Wamboldt, Gavin, & Wamboldt, 2002; Mansfield, Keitner, & Dealy, 2015). The FAD has good internal consistency, ranging from 0.72 to 0.92. The correlation between the six dimension scales ranges from 0.4 to 0.6.

An explanation of the administration and completion of the scale can be found in Georgiades et al. (2008). The FAD consists of 12 statements in each dimension that describe family behaviour and relationships. The respondents' options for each statement are 1 = *strongly agree,* 2 = *agree,* 3 = *disagree*, and 4 = *strongly disagree*. After recoding positively oriented items, the total of the item scores forms a total score, which could range from 12 to 48. Higher scores are indicative of better functioning. Researchers have used this instrument in South African studies (Botha et al., 2009).

4.9 Qualitative Data Collection

Family interviews were conducted and the Graphic Family Sculpting (GFS) was administered to obtain qualitative data (Venter, 1993). These were supplemented by the researcher's field notes. By employing this approach, the researcher was able to explore multiple realities and perceptions co-constructed by people (Chamberlain, 2015; Grove, Gray & Burns, 2015; Creswell, 2014).

4.9.1 Family Interview

The aim of the face-to face interview with the patients and their family members was to examine, gain insight into and understand the processes of family *life* while focusing on family processes and family functioning (Creswell, 2014). The researcher created an environment of trust and openness in which the participants were able to express their views openly (Hatzipapas, Visser, & Janse van Rensburg, 2017). The interview was planned carefully with possible questions and probes, even though it was semi-structured, to offer interviewees the opportunity to expand their answers and share complex accounts of their experiences (Forrester & Sullivan, 2018; Willig, 2013). The researcher wanted to create meaning and comprehension found in qualitative research, and monitor responses and emotions (Irvine, Drew, & Sainsbury, 2013). The Interview Schedule can be found in Appendix F.

People communicate with body language and speech, which the researcher wanted to observe when assessing the family (Fielding & Thomas, 2008; Novick, 2008). The participants participated with ease and thus, the researcher found it was possible to facilitate an interview to ensure a rich and in-depth description of the family's processes and functioning. The families and participants welcomed the opportunity to talk about their experiences; prompting, minimum verbal and non-verbal responses and encouragement were sometimes all some of the participants needed to continue talking so the objectives of the research could be achieved. The focus was on the here and now. The researcher also allowed the family to choose who spoke, but also tried to involve all members present. The researcher paraphrased, clarified, reflected on and summarised the participants' answers. Each family interview lasted between 30 and 90 minutes. The process information resulted in a qualitative description of the family. From the interviews, the researcher sorted the data into codes, sub-themes, themes and main overarching themes.

4.9.2 Graphic Family Sculpting (GFS)

The GFS was used as a technique to gain information on family processes and the functioning of the families by examining family interactions, roles and processes. GFS, a modified form of family sculpting, is a projective and diagnostic technique developed by Venter (1989, 1993) with the purpose to redefine complex and often vague family issues in a simple, workable form. During the application, participants were required to draw their family by following specific instructions; these are included in Appendix G (Venter, 1993, 2014; Venter, Van Rensburg, & Du Plessis, 1997).

During the application and interpretation of GFS, family members are intellectually involved in studying material with a high emotional content and are able to acquire new knowledge about the information they provide (Venter, 1993). Participants can get to know themselves and their families better; although not part of the research objectives, some of the participants shared that this was what they experienced. The researcher, who received training in how to administer GFS, applied the technique in accordance with that of the developer. Furthermore, the developer gave the researcher permission to use the technique as part of the research (Venter, 1993; 2014; Venter et al., 1997). In this study, the family members completed the GFS in a conjoint session with all participating members of their family; however, they were not allowed to consult each other while giving their own confidential representation. The GFS took between 30 and 60 minutes to administer. Construct validity as well as other types of research studies that had employed GFS were taken into account for use in this study. GFS measures other factors than those measured by other well-known measuring instruments for families (Venter, 1993). Van Hoek (1991) concluded that GFS exhibits a degree of validity and is multi-dimensional.

Previous relevant research done with GFS includes:

- Research done on African female adolescents in which their experience of parenting and sense of well-being was explored (Koen, Van Eeden, & Venter, 2011).
- Used as a technique in family therapy with possibilities of use in a family setting (Venter, 1993).
- Used as part of a pre-marital enrichment programme (Venter, 1989).
- Employed to assess to what extent individuals' experiences are from processes innate to certain psychological theories on the nature of psychotherapy (Venter, Du Toit, & Du Toit, 2002).
- Assessment of the impact of GFS on individuals' perception of their families of origin (Venter et al., 2002).

- GFS found to be reliable with adolescents to explore family processes; researchers used it in a South African study with African participants (Marchetti-Mercer & Cleaver, 2000).

In this study, GFS was employed to explore family processes and the functioning of families. The *gestalt* or wholeness of the sketches is of importance as it comments on the placement of each family member in the *gestalt* and relates to family systems theory where the researcher views the whole as more important than the individuals within the family system.

4.9.3 Field Notes

The researcher wrote field notes immediately after each interview and focused on observations she had made (Emerson, Fretz, & Shaw, 2001; Taylor, Bogdan, & De Vault, 2015). The purpose of these notes was to record the family processes and family functioning experienced in the family. These notes form part of Appendix H. The analysis of the field notes was performed in relation to occurring and reoccurring themes and was incorporated as part of the analysis of the family interview. Thus, the focus was on the interview as a whole as well as the impressions it made on the researcher.

The researcher included reflexive notes on epistemological reflexivity, reflections on the researchers' personal responses, and the researchers' theoretical and paradigmatic stance and how it may have influenced the responses (Taylor et al., 2015; Todd et al., 2004; Willig, 2013, 2014). Because of employing a systemic approach, it was important for the researcher to reflect on her influence on each family system that was interviewed. This forms part of the researcher's quality control and is included in Chapter 6 in conjunction with the interpretation of results.

4.10 Pilot Study

A pilot study on two families who met the selection criteria was conducted with the purpose of evaluating the efficacy of the data collection strategy, applicability and ease of administration of measuring instruments (Denscombe, 2014; Neuman, 2014). The participants were very willing to participate in the family interview. The family members appeared to welcome the opportunity to share their experiences of epilepsy as a family as well as their experience of it in their family. The participants indicated that they found the GFS interesting. Furthermore, it opened new insights on how they experienced themselves and the members of their family in general. They perceived the measuring instruments to be user friendly, easy to understand and could complete them easily in the given format. It took them approximately 30 minutes to complete the questionnaires. The research consultant noted that it seemed that the participants easily understood how they had to interact with the questionnaire. Consequently, it was easy to process the quantitative data for the pilot study. The data collection could proceed and the protocol for the pilot study was sufficient.

4.11 Data Analysis Strategies

Qualitative and quantitative data analyses were conducted to compare themes in both types of data for the purpose of triangulation.

4.12 Quantitative Data Analysis

Statistical analysis of the data included descriptive statistics, non-parametric tests, namely, Wilcoxon signed rank sum test (Albright, Winston, & Zappe, 2009; Breakwell, Smith, & Wright, 2012) and Kruskal-Wallis test (Allbright, Winston, & Zappe, 2009; Breakwell, Smith, & Wright, 2012; Green & Salkind, 2008), and correlation coefficients. Because of the sample size, scale of variables and distribution of data, non-parametric tests were used. The patients and their families' scores of 13 and not 15 families were compared, as there were 13 families where the patient and at least one family member participated. With two families only a family member participated. The statistical analysis comprised descriptive statistics such as the mean, standard deviation and median. Single frequencies and frequencies based on multiple responses were used to create groups and combinations of responses for the biographical information. This information described the family process profiles of the families and the patients.

The Kruskal-Wallis test was used to determine within patient group differences by comparing the total of the median scores of the scales and subscale scores for the patients across the sociodemographic variables, which were mostly categorical. This was done to establish whether patients with different sociodemographic characteristics displayed different family process profiles. The sociodemographic variables included age, gender, family income, parents' marital status, family structure, clinical information, duration of diagnosis and type of epilepsy.

The non-parametric Wilcoxon signed rank sum test for paired observations was used to compare the family members and patients' median total and subscale scores on measures of family satisfaction, family functioning and hardiness. Since the patient and family scores on scales and subscales were paired measurements (each patient linked to his or her family), comparisons on paired or repeated measurements were performed.

The calculation of correlation coefficients so as to investigate the relationships between the scales and subscales of the psychometric tests was performed last. These coefficients were calculated for all the families (n=15), all the patients (n=13) and for the patients with their related families (n=13). Calculation of the non-parametric Spearman's rho correlation coefficient was used to describe the relationships between the scales and subscales. The p-values reported with each correlation coefficient tested the null hypotheses that the population correlation coefficient is equal to zero; in other words, there was no relationship between the two scales or subscales. A p-value that was smaller than 0.05 indicated a significant correlation between two subscales or scales. The analyses were performed using the IBM SPSS Statistics (Green & Salkind, 2008; Neuman, 2014) version 23-computer package.

The total score for interpretation of the FSS, FFS and FHI as well as the total score on the General Functioning scale of the FAD was used for the analyses.

4.13 Qualitative Data Analysis

4.13.1 Family Interview

The interviews were video-recorded; the researcher watched the video recordings and noted further impressions on the themes set out in the research objectives. After completion of all the interviews, the researcher watched all the video recordings several times again, one after the other, in an attempt to identify themes from the same angle during a specific time to ensure some form of reliability. Inductive thematic analysis was used to organise themes where the coding frame itself emerged from the data to support the research question (Willig, 2013, 2014). First, general themes were identified from topics that were repeated to get a sense of the whole (Creswell, 2014; Taylor et al., 2015). Subsequently, specific themes related to the research question were identified. Thereafter, global themes, and the most descriptive wording for the topics for the formulation of categories (Creswell, 2014) and grouping in conjunction with summarizing categories were identified (Imran & Yusoff, 2015).

4.13.2 GFS

After each session, the researcher examined the particular family's GFS and made short notes on obvious themes. Each family's GFS was analysed after completion of all the interviews by identifying and writing down themes. The researcher and co-coder agreed on an approach to the analysis beforehand so as to ensure consistency, reliability and trustworthiness of the categories; this was in accordance with prescribed guidelines for the

GFS as determined by the developer (Koen et al., 2011; Venter, 1989, 1993, 1994, 2014; Polit & Hungler, 1987). The combination of the analysis performed by the researcher and co-coder yielded a description of the GFS that formed part of the qualitative data gathering. For consistency across families, the researcher chose to analyse the GFS of the patient and one family member; preferentially the primary caregiver when available. In most families, the participants were represented by the patient and primary caregiver. In three families (Family 3, Family 8 and Family 13), only the primary caregiver participated. Furthermore, in Family 15 only the patient drew a GFS and in Family 14, only the patient and two of her siblings participated.

The following themes and methods of analysis were focused on:

1. Examine each family's GFS as a whole to ascertain if anything obvious or interesting stood out.
2. Analyse each GFS according to the following fields:
    - The order in which the persons were drawn (participants had to number them in the order that they drew them) and the size and differences in the circles of persons (what does it say about power and importance in the family);
    - The gestalt of the sketch and the position of the persons in the sketch;
    - The horizontal positions and behaviour of the persons (lying down, sitting, standing);
    - The direction in which the persons are looking;
    - Comments on the marital subsystem;
    - Comments on the children and sibling subsystem;
    - Comments on the labels (what it entails regarding the leadership role in the family, strength of members, especially the patient);
    - Comments on the emotions (whether they are *welfare* or *emergency* emotions); and
    - Anything else of interest or that stood out.
3. Describe the general impression of the data as a whole.
4. Analyse each GFS of each family again to note finer detail regarding the fields as set out in step 2.

Conclusions were made about the marital and child subsystems as well as important information about members' relationships with one another when examining the direction in which each member was looking. The horizontal or vertical position of each family member may have suggested the person's power or assertiveness. It was necessary to note the order in which the circles were drawn and the size of the circles as well as the line quality as these serve as an indication of the role that was played by each member in the family. Classification of the emotions allocated to family members were predominantly positive or negative during analysis. Examples of administered GFS and its analysis are included in Appendix V1 – V3.

4.14 Integration of Quantitative and Qualitative Results

The quantitative and qualitative results were integrated and differences and similarities in the quantitative and qualitative findings were elaborated. This is detailed in Tables 5.19 and 5.20. The data were further analysed and the quantitative results, namely, the concordance of family process ratings and other important variables, and the qualitative findings, namely, the 12 major themes derived from the qualitative themes, were integrated. These are presented in Table 4.6. The descriptive statistics of the variables for each of the quantitatively derived groups for purposes of comparison among the different qualitative perspectives are presented in the table. In order to relate the two data sets, the quantitative and qualitative data sets were analysed separately. Both types of data were regarded as equally important to address the study's purpose. After the initial separate analyses, the two sets of results were merged in an interactive way so that the point of interface occurred during the analysis and the interpretation.

Table 4.6

Merging of Quantitative Results and Qualitative Findings

Rigorous quantitative data analysis procedures	General procedures in data analysis	Persuasive qualitative data analysis procedures
- Quantitative results give more detail regarding the family process profiles consisting of family satisfaction, family functioning, and hardiness as reported by the patient and family members. Explanation of differences between patient and family members' process profiles is presented in Table 5.7.	Interpreting the results	- The qualitative research question can be answered by giving details regarding how families experience living with an adolescent diagnosed with epilepsy. See Table 5.18 regarding the impact of epilepsy on the family process and functioning according to the patient and family members.
- Use external standards - Validate and check the reliability of scores from past instrument use - Establish validity and reliability of current data - Assess the internal and external validity of results	Validating the data and results	- Use researcher, peer review and reviewer standards – co-coder was appointed for GFS - Use validation strategies, triangulation, disconfirming evidence, and external reviewers - Check for the accuracy of account - Employ limited procedures for checking reliability

4.15 Quality Assurance Of Qualitative and Quantitative Data

Quality assurance of qualitative and quantitative data is important in mixed method designs because it is important to be able to trust the obtained results, conduct research of a high standard (Creswell, 2014, 2015; Flick, 2018; Forrester & Sullivan, 2018; Kerr, Nixon, & Wild, 2010) and ensure ethically appropriate research (Curry & Nunez-Smith, 2014; Flick, 2018; Todd et al., 2004). The following criteria were applied to both qualitative and quantitative parts of the study (Elliot, Fischer, & Rennie, 1999): owning one's perspective, disclosure of own assumptions and values of the researcher affords the reader the opportunity to consider possible alternative interpretations.

- Situating the sample: Participants and their life circumstances were described in detail. The reader is able to consider the applicability and relevance of the findings.
- Grounding in examples: Examples of data demonstrated the analytic procedures used and the understanding that they generated.
- Providing credibility checks: Referral to other researchers, colleagues and participants in relation to the interpretation of the data and applying other methods of analysis.
- Coherence: Analysis presented for coherence and integration by keeping the character of the data.
- Accomplishing general versus specific research tasks: By being clear about the research tasks and by pointing out limitations.
- Resonating with readers: By presenting material in a stimulating way and expanding the readers' understanding of the research matter.

For quality assurance of quantitative data, the researcher only used standardised scales with high validity and reliability that have often been used in research with families and family therapy settings in order to collect quantitative data (Baez, 2000; Botha et al., 2009; Brown et al., 2010; Carver & Jones, 1992; Cashwell & Vacc, 1996; Greeff & Van der Merwe, 2004; Koen, 2009, 2012; Mansfield et al., 2015; McCubbin et al., 1991; Pillay & Wassenaar, 1997; Robinson, 2003; Roux, 1997). Quantitative data was collected from participants in the same geographical and demographic contexts as all the participating patients consulted neurologists at private hospitals in the same geographical region.

For quality assurance of qualitative data, the researcher tried to be transparent in the research process, steps and decisions that influenced the production of data and results (Flick, 2018; Taylor et al., 2015). Furthermore, she explained to participants that they were experts on epilepsy and requested their informed opinions when sharing their experiences of epilepsy in their family. The researcher tried to conduct interviews with appropriate validity for the purpose of this study. Moreover, the interview questions were related to the research question (Neuman, 2014; Taylor et al., 2015; Todd et al., 2004). The researcher considered dependability, consistency and auditability of the data during data coding so as to identify substantial themes to analyse and from which to draw conclusions (Onwuegbuzie & Leech, 2004; Woods & Catanzaro, 1988).

The researcher considered the following (De Vos, 2002; Henwood, 2014; Lincoln & Guba, 2013; Taylor et al., 2015; Woods & Catanzaro, 1988):

- The analytic categories had to fit the data well and explicit, clear and comprehensive accounts of why certain labels and categories were utilised had to be substantiated.
- The integration of theory into analysis and an explanation of the rationale.
- Reflexivity in acknowledging the role of the researcher in the documentation of the research.
- Giving an inclusive and thorough description throughout the research process of what was done and why.
- Exploring cases that could generate new insights, that is, theoretical sampling and investigating those that may not be applicable, namely, negative case analysis.
- Sensitivity to negotiated realities, awareness of the reactions of the participants and an openness to the manner in which participants might experience reality.
- Reporting the contextual features of the study in full to allow readers to explore applicability beyond the context of the generation of data and creating transferability.

From a technical perspective, the researcher formulated the questions and probes in a manner that ensured the interview helped to address the relevant issues.

4.16 Ethical Considerations and Principles

Ethical considerations in qualitative, quantitative and mixed methods research were applicable to this study and included informed consent, no deception, right to withdraw, debriefing and confidentiality (Creswell, 2014; Willig, 2013). An examination of the researcher's professional association and professional insurance standards and codes of ethics was conducted. Ethical clearance was obtained from the Ethical Committee of the University of Pretoria (Appendix I). Permission from the hospital group where the participating neurologists had their practices (attached as Appendix J) was granted to conduct the study. Furthermore, the referring neurologists were given permission to refer their patients to participate in the study (Appendix K). The purpose of the study was disclosed to the referring neurologists and potential participants by means of an information leaflet and by not deceiving participants (Neuman, 2014). The researcher arranged for an independent psychologist to be available for referral of participants for psychotherapy should the need arise through the research process (Appendix L) (Willig, 2013). The co-coder agreed to the confidentiality and ethical considerations (Attachment X).

The researcher was clear that the relation between the researcher and participants was a research relation and not therapy nor friendship, and it had an end-point (Flick, 2018; Taylor et al., 2015; Willig, 2013). Participants gave informed consent in the form of a written and signed contract, and participated voluntarily (Appendix M). Furthermore, they were assured they could have access to any publications arising from the study (Neuman, 2014; Willig, 2013). The informed consent includes information that participants were free to withdraw from participation in the research without fear of being penalized in any way, and that their data would be destroyed if they withdrew (Flick, 2018; Willig 2013). The participants' parents provided written consent for minors (Appendix N). The participants also gave consent to have their interview video-recorded. The researcher guarded against misconduct and focused on privacy, confidentiality, credibility of the research report, and sensitivity towards participants from different cultures and vulnerable populations (Israel & Hay, 2006; Neuman, 2014; Newton, 2010; Willig, 2013). Identifying particulars such as names from the transcripts, questionnaires and GFSs were removed and replaced by pseudonyms.

The researcher recommended psychotherapy to Family 3, Family 4, Family 5, Family 10, and Family 11. With Family 11, it was necessary to act immediately as the patient suddenly experienced an emergency because of previous latent unaddressed emotional issues and the researcher made contact with a psychiatrist to arrange admission to a psychiatric hospital. This is discussed in detail in the field notes of Family 11. Boundaries of confidentiality were broken in this case so as to act in the safety and best interests of the patient.

4.17 Validity

Mixed methods enhance the validity of the results (Creswell, 2014, 2015; Johnson & Onwuegbuzie, 2004). In terms of quantitative validity, construct validity seemed to be satisfactory as the measures of the scales represented the expected concepts. It was difficult to compare the new measures with the existing measures because the questionnaire as a battery was compiled by the researcher and not used in previous research as a battery. The measures of FSS, FFS, FHI and FAD correlate with existing measures of the same concept and have convergent validity. Qualitative validity through triangulation occurred for the qualitative database. The use of different concepts on both sides, quantitatively and qualitatively, may be incomparable and difficult to merge findings (Creswell, 2014).

4.18 Conclusion

In this chapter, the research methodology, design and approach, including the quantitative-, qualitative- and mixed methods research questions, were described. Furthermore, the aim and objectives, the philosophical worldview of critical realism,, the rationale for using mixed methods research, as well as the triangulation design and convergence model, were described. This chapter concluded with a description of the integration of the quantitative- and qualitative results and the ethical considerations and validity issues taken into account. In the next chapter, the findings are presented.

CHAPTER 5: RESULTS

The results outlined in this chapter are organized around the quantitative and qualitative research aims of this study. The quantitative aims involved determining the family process profiles, namely, family satisfaction, family functioning and hardiness, which were reported by the patients and their family members. The qualitative aims involved exploring the patients and family members' perceptions of how families experience living with an adolescent diagnosed with epilepsy as well as the impact epilepsy has on the family processes and overall family functioning. The researcher compared the differences between the patients and family members' family process profiles. A brief description of each family, a summary of the characteristics of the group, and thematic analyses of the interviews and the GFS follow; in accordance with the qualitative aims of the study, the identified themes of the group as a whole are included.

5.1 Quantitative Findings

The quantitative findings are described in terms of the descriptive data and inferential analysis.

In the section on descriptive data, the patients and family members' sociodemographic characteristics as well as a comparative analysis of the scores obtained from the measuring instruments (FSS, FFI, FHI and FAD) for the patient group and family group are documented. Patients and family members were classified into groups only for statistical purposes. Analyses included within group analysis, that is, patients, and between group analyses, that is, between patients' scores and family scores. In order to establish if there were significant differences between family process profiles reported by the patients and family members, the researcher performed a number of inferential analyses.

5.1.1 The Characteristics of the Participants

All the participants who had been referred by their treating neurologists and who had met the selection criteria were included in the study. The researcher conducted interviews with 15 families. In 13 of the families, at least one parent was present, in one no parent was present but two siblings attended with the patient, and in one only the patient was present for the interview. Twelve patients as well as a family representative from each family completed questionnaires. The sociodemographic profile of the patients and their families follow.

5.1.1.1 Description of the family profile (N = 15).

The family members were required to provide biographical information (Section A of the family questionnaire, see appendix A). Most of the patients lived in nuclear families. There was an average of 4.4 family members per family (SD=1.2; Range 3 to 7). Most patients lived with their parents; although they were mainly biological (60%), there were some stepfathers. Most of the parents were married (86.7%). Furthermore, most of the fathers and mothers were employed full-time. Most of the participants were White (86.7%). Although the majority of the families had a total household income of R100 000 or more per month (26.7%), six families (40%) had a total household income of less than R30 000 per month. The participants were largely middle class White people. Moreover, they were a relatively well-educated group. According to the family members, the patients had had a diagnosis of epilepsy for an average of 35.67 months (SD=26.2; Range: 2 to 84) even though some patients indicated a shorter duration period since the epilepsy diagnosis. However, the family members' information in this instance was considered a more reliable indicator because the primary caregivers appeared to be more informed than the patients with respect to communication with the neurologists.

5.1.1.2 Description of the patient profile (N = 13).

The following biographical information about the patients' profiles was obtained from Section Aof the patient questionnaire. Only 13 patients of the 15 families participated. The average age of the patients was 15.9 years (SD=1.34; Range 14 to 18). Most of the patients were female (61%) and White (76.9%). After school, most did not stay at home with a parent or adult or at an after-school centre (38.5%), but had made other arrangements. Most of the patients participated in sports and religious activities as extra-mural activities (30.8%). In fact, they all participated in at least one extra-mural activity and more than half of the patients participated in more than one extra-mural activity. Most of the patients (66.7%) had been diagnosed with generalized idiopathic epilepsy and epileptic syndrome by their neurologists. The remaining participants had been diagnosed with another variation of epilepsy. A graphic summary of the diagnoses of the patients as made by the treating neurologists is depicted in Figure 5.1.

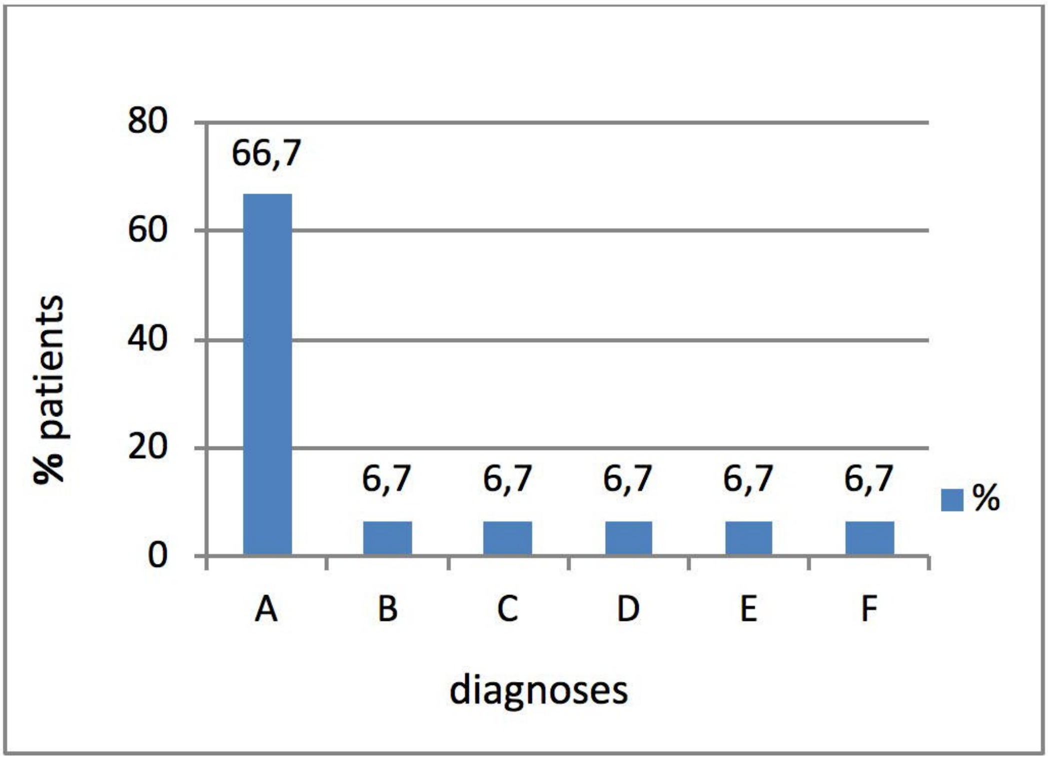


Figure 5.1. Diagnosis of patients as made by the treating neurologists

Note. Percentage bars represent the percentage of participants diagnosed with a specific type of epilepsy as made by the treating neurologists. Alphabetical letters indicate diagnosis. A: Generalised idiopathic epilepsy and epileptic syndrome; B: Localised-related symptomatic epilepsy with complex partial seizure; C: Localised-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset; D: Dissociative conversion disorder and other and unspecified convulsions; E: Epilepsy; F= Epilepsy (?) and dissociative conversion disorder.

5.1.2 Comparison Between Patient Profiles and Family Profiles

In Table 5.1, the results and analysis of the scores of each family and the corresponding patient for family satisfaction, hardiness and functioning are presented. In Appendix P, the results are presented by family and for the families as a group. The researcher did this to compare the quantitative results with the qualitative results. The totals in this table are the total percentiles for FSS and raw scores for FFS, FHI and FAD, which were used for qualitative interpretation of levels of functioning. These levels were determined according to the classifications of high, average and low based on the classification in test manuals as well as grouping into categories created by the researcher to be able to compare high and low scores across questionnaires. All the scores for all the scales were calculated and can be found in Appendix Q.

Table 5.1

Family and Patient Unit Percentiles for FSS and Raw Scores for FFS, FHI and FAD

Family units	**Unit 01**		**Unit 02**		**Unit 03**		**Unit 04**		**Unit 05**		**Unit 06**		**Unit 07**		**Unit 08**		**Unit 09**		**Unit 10**		**Unit 11**		**Unit 12**		**Unit 13**		**Unit 14**		**Unit 15**	
	Family	**Patient**	**Family**	**Patient**	**Family**	**Patient**	**Family**	**Patient**	**Family**	**Patient**	**Family**	**Patient**	**Family**	**Patient**	**Family**	**Patient**	**Family**	**Patient**	**Family**	**Patient**	**Family**	**Patient**	**Family**	**Patient**	**Family**	**Patient**	**Family**	**Patient**	**Family**	**Patient**
FSS																														
Total: Satisfaction	79	37	73	40	1	1	94	91	61	70	37	19	61	1	22	-	28	55	1	31	52	16	91	46	43	-	88	67	43	85
	H	M	H	M	VL	VL	VH	VH	H	H	M	VL	H	VL	L	-	L	M	VL	L	M	VL	VH	M	M	-	VH	H	M	H
FFS																														
Total: Functioning	79	80	77	75	68	55	91	69	80	79	85	37	86	53	70	-	65	60	62	84	73	41	80	66	72	-	80	65	55	74
	H	H	H	H	H	A	H	H	H	H	H	A	H	A	H	-	A	A	A	H	H	A	H	A	H	-	H	A	A	H
FHI																														
Total: Hardiness	54	74	66	54	66	71	70	67	68	70	69	53	69	42	60	-	58	39	60	69	60	43	67	59	68	-	70	65	57	62
	A	H	A	A	A	H	H	H	H	H	H	A	H	A	A	-	A	L	A	H	A	A	H	A	H	-	H	A	A	A
FAD																														
Total: General functioning	1.50	1.42	2.08	2.17	2.58	1.75	1.42	1.42	1.67	2.00	2.17	2.92	1.75	2.58	1.67	-	2.25	2.42	2.58	2.17	2.58	2.92	1.33	2.42	1.25	-	1.25	1.50	2.17	1.92
	H	H	M	M	M	H	H	H	H	H	M	M	H	M	H	-	M	M	M	M	M	M	H	M	H	-	H	H	M	H

Note. **FSS**: *VH = very high*, *H = high*, *M = moderate*, *L* = low, *VL = very low* / **FFS**: *L = low*, *A = average*, *H = high /* **FHI**: L = *low*, *A =average*, H = *high*

FAD: *H = healthy*, *M = middle between healthy and unhealthy*

All dark grey highlighted letters represent *high* or *very high,* and *low* or *very low*.

A study of the information presented in Table 5.1 reveals the following. On the FSS, seven families, in comparison with four patients, felt highly satisfied with their families. On the FFS, 12 families, in comparison with five patients, were functioning well. On the FHI, five families and five patients believed that their families had high hardiness. On the FAD, eight families, in comparison with six patients scored high on general functioning.

5.1.2.1 FSS.

When the score of the FSS is very high, family members are very satisfied and enjoy most aspects of their family. When the score is very low, family members are very dissatisfied and are concerned about their family. Families that have high scores on balanced cohesion and balanced flexibility will have higher levels of family satisfaction. Families with high scores on the unbalanced scales will have lower levels of family satisfaction. Therefore, balanced families will have significantly higher family satisfaction than unbalanced families (Olson, 2010). Families high in family satisfaction will have significantly better family communication than families low in satisfaction (Olson, 2010).

Seven out of 15 families felt that their levels of cohesion and adaptability were satisfactory, were more balanced and generally functioned more adequately. These families experienced satisfactory levels of cohesion within their family in relation to emotional bonding, family boundaries, coalitions, time, space, friends, decision- making, interests and recreation. They also experienced satisfactory levels of adaptability in relation to assertiveness, control, discipline, negotiation, roles and rules. Two families were very dissatisfied and concerned about their families and were not satisfied with their levels of cohesion and adaptability. Four patients experienced satisfactory levels of cohesion and adaptability, and enjoyed most aspects of their family. Four patients were not satisfied about their levels of cohesion and adaptability, and were very dissatisfied and concerned about their families. The rest of the scores fell in the mid-range categories of the scale and demonstrated high, moderate and low scores.

5.1.2.2 FFS.

When the FFS score is high, there will be high tendency to characterize families by their different strengths and capabilities. Compared to 12 families, five patients experienced a high level of adaptive functioning that characterizes families by different strengths and capabilities. Two families in comparison with seven patients experienced an average level of adaptive functioning that characterizes families by different strengths and capabilities.

5.1.2.3 FHI.

When the FHI score is high, the family is characterized as having high levels of hardiness as a stress resistance and adaptation resource. This resource may function as a buffer or mediating factor in mitigating the effects of stressors and demands, and a facilitation of family adjustment and adaptation over time (McCubbin et al., 1991 McCubbin & Thompson, 1991; McCubbin, Thompson, Pirner & McCubbin, 1988).

Hardiness applied to families reflects the basic strength they rely on to manage the hardships and difficulties of transitions and crises. On the FHI, five families and five patients experienced high hardiness in their families. One patient experienced low hardiness in his or her family compared to the scores for his or her family, other patients or in comparison to other families. Eight families and seven patients experienced average hardiness.

5.1.2.4 FAD.

On the FAD, the total general functioning score assesses the overall health or pathology of the family. A total score can range from 1.0 (best or healthy functioning) to 4.0 (worse or unhealthy functioning). On the FAD, eight families, in comparison with six patients, scored high on general functioning, thus, indicating healthy family functioning. The scores of seven families and seven patients were between unhealthy and healthy functioning.

5.1.2.5 Summary of scores of all scales.

A summary of the classification of very high and high scores (*highs)* and very low and low scores (*lows*) per family or patient according to the four scales is presented in Attachment Q. In Table 5.2, a summary of results obtained from all the scales so as to acquire an impression of the **family process profiles** is provided.

Table 5.2

Comparative Analysis Between Patient Profiles and Family Profiles

Participants	FSS	FFS	FHI	FAD	Family process profiles
Patients	4 felt satisfied with their families 4 felt dissatisfied	5 experienced high functioning of families 7 experienced average functioning	5 experienced high hardiness of families 1 experienced low hardiness 7 experienced average hardiness	6 experienced healthy functioning of families 7 experienced average functioning	3 experienced profiles to be better than the families' experience of it
Family members	7 felt satisfied with their families 2 felt dissatisfied	12 experienced high functioning of families 2 experienced average functioning	5 experienced high hardiness of families 8 experienced average hardiness	8 experienced healthy functioning of families 7 experienced average functioning	8 experienced profiles to be better than the patient experience of it

The researcher made the following observations. Eight families experienced the family process profiles (family satisfaction, family functioning, and hardiness) of their family to be better than the patients' experience of it. Three patients' experience of the family process profiles of their family were better than their family's experience of it. It appeared as though family members were more satisfied with how they experienced their families than patients were. The majority of patients' experience of their family's functioning was not very satisfactory. The families and patients had mainly similar experiences of their family's hardiness. Overall, it appeared that the family members' experience of the general functioning of the families was better than that of the patients. More family members' experience of the family process profiles of their family was better than the patients experience of it (refer to Tables 5.1 and 5.3).

The descriptive statistics for the family and patient groups, that is, 13 families and their corresponding patients are summarized in Table 5.3.

Table 5.3

Descriptive Statistics on FSS, FFS, FHI and FAD for Family and Patient Groups

Measure	**Group**					
	Family Members Mean			**Patients**		
		SD	**Range**	**Mean**	***SD***	**Range**
FSS: Cohesion	46.23	32.58	1-94	37.69	29.01	1-94
Adaptability	70.23	24.45	34-94	58.23	30.16	19-94
Total Satisfaction	**54.54**	**31.51**	**1-94**	**43.00**	**29.65**	**1-91**
FFS: Family Identity	26.08	4.37	18-32	21.69	5.95	12-28
Information sharing	12.00	2.20	9-16	10.46	3.64	3-14
Coping/resource mobilization	37.38	4.77	27-44	32.31	7.12	22-43
Total Functioning	**75.46**	**10.37**	**55-91**	**64.46**	**14.73**	**37-84**
FHI: Total Hardiness	**64.15**	**5.57**	**54-70**	**59.08**	**11.92**	**39-74**
FAD: Problem solving	1.94	0.36	1.20-2.40	2.23	0.64	1.40-3.20
Communication	2.12	0.38	1.50-2.84	2.38	0.57	1.67-3.83
Roles	2.30	0.42	1.75-3.00	2.55	0.32	2.13-3.25
Affective responsiveness	2.18	0.38	1.50-2.83	2.51	0.55	1.67-3.33
Affective involvement	2.10	0.46	1.29-2.86	2.35	0.33	1.71-2.86
Behavioural control	1.68	0.38	1.11-2.11	2.00	0.53	1.22-2.89
Total General Functioning	**1.95**	**0.49**	**1.25-2.58**	**2.12**	**0.52**	**1.42-2.92**

Note. FSS: Family Satisfaction Scale; FFS: Family Functioning Scale; FHI: Family Hardiness Index; FAD: Family Assessment Device; *SD* – Standard Deviation.

In 13 of the 15 cases, information was obtained from both the family and the patient. The information in the table reflects the descriptive statistics and the results of the Wilcoxon signed rank test of these 13 pairs. *n* = 13.

The discrepancy in total scores is an interesting result and makes sense when considering the contributions of the subscales. The mean was higher for family members than patients on levels of family satisfaction, family functioning and hardiness. This indicates the family members had higher satisfaction, higher functioning and higher hardiness than the patients. Higher scores present better outcomes. More family members felt highly satisfied with their families than the number of patients who did. The majority of families functioned better than the patients did. In terms of hardiness, the families and patients fared the same and experienced the hardiness of their families as fair. On general functioning, the patients reported higher scores and subsequently, better outcomes than family members. Therefore, the patients experienced themselves functioning better overall than how they experienced the functioning of their family members. As noted previously, although 15 families participated in the study, two patients did not complete the questionnaires. Comprehensive tables are included in Appendix P.

5.1.3 Comparative Analysis Within the Patient Group

The non-parametric Kruskal-Wallis test was used, as part of the inferential analysis, to determine if patients with different sociodemographic and clinical profiles performed differently on the family satisfaction, functioning and hardiness scales. The classification of sociodemographic variables is provided in Table 5.4.

Table 5.4

Sociodemographic Variables

Sociodemographic variables	**Age**	**Gender**	**Diagnoses duration**	**Household income**	**Diagnostic profile**	**Family unit**
Categories	14 to 16 years	Male	2 to 12 months	R0 to R29 000	Generalized	Both parents
	17 to 18 years	Female	13 to 24 months	R30 000 to R69 000	Localized	Single parent
			25 to 36 months	R70 000 and more	Conversion / Epilepsy	Extended family
			37 to 48 months		Seizures	
			49 and longer months			

No significant differences were found in family process profiles for patients with different diagnostic profiles, illness duration, family composition, and household income.

A significant gender difference was found on the Coping 1 subscale (p=.037). The mean FSS score for male and female patients was 5.00 and 3.25, respectively, indicating that the male patients were coping better. The Kruskal-Wallis test also indicated significant differences between age and a subscale score within the FSS.

Significant differences were found across the two age categories for the adaptability subscale of the FSS (p = 0.029) and on total family satisfaction (p = 0.045) (refer to Table 5.5 below). A summary of the results of the non-parametric Kruskal- Wallis test so as to compare mean scores across the two age categories appears in Table 5.5.

Table 5.5

Results of the Non-parametric Kruskal-Wallis test to Compare Mean Scores Across Age Variables

Measure	**Patients**								**Kruskal-Wallis Standarized Test statistic (Z) *p*-value**	
	14 to 16 years				***17 to 18 years***					
	Median	**Mean**	***SD***	**Range**	**Median**	**Mean**	***SD***	**Range**		
FSS: Cohesion	19.00	29.00	24.46	1-70	59.50	57.25	32.16	16-94	2.185	0.139
Adaptability	37.00	46.00	28.26	19.94	88.00	85.75	7.09	76-91	4.745	0.029*
Total Satisfaction	**31.00**	**32.33**	**27.17**	**1-85**	**68.50**	**67.00**	**20.93**	**40-91**	**4.035**	**0.045***
FFS: Family Identity	19.00	19.78	6.06	12-27	27.00	26.00	2.83	22-28	3.496	0.062
Information sharing	9.00	9.56	3.97	3-14	12.50	12.50	1.73	11-14	1.631	0.202
Coping/resource mobilization	32.00	31.78	7.55	22-43	33.50	33.50	6.95	27-40	0.293	0.588
Total Functioning	**60.00**	**61.11**	**16.44**	**37-84**	**72.00**	**72.00**	**6.22**	**65-79**	**1.167**	**0.280**
FHI: Total Hardiness	**60.00**	**62.22**	**5.61**	**54-69**	**69.00**	**68.50**	**1.92**	**66-70**	**0.595**	**0.440**
FAD: Problem-solving	2.60	2.44	0.62	1.40-3.20	1.70	1.75	0.41	1.40-2.20	2.937	0.087
Communication	2.17	2.54	0.61	2.00-3.83	2.08	2.04	0.28	1.67-2.33	1.789	0.181
Roles	2.50	2.50	0.29	2.13-2.88	2.50	2.66	0.41	2.38-3.25	0.222	0.637
Affective responsiveness	2.50	2.56	0.58	1.83-3.33	2.50	2.42	0.55	1.67-3.00	0.098	0.754
Affective involvement	2.29	2.44	0.29	2.14-2.86	2.21	2.14	0.35	1.71-2.43	1.200	0.273
Behavioural control	2.11	2.12	0.57	1.22-2.89	1.67	1.72	0.33	1.44-2.11	1.536	0.215
Total General Functioning	**2.42**	**2.28**	**0.51**	**1.42-2.92**	**1.75**	**1.77**	**0.37**	**1.42-2.17**	**2.407**	**0.121**

Note. FSS: Family Satisfaction Scale; FFS: Family Functioning Scale; FHI: Family Hardiness Index; FAD: Family Assessment Device; *SD:* Standard Deviation. *Z* = Kruskall Wallis score.

* *p* ≤ 0 .05; *n* = 13.

5.1.4 Comparative Analysis Between Family and Patient Groups

The results of the non-parametric Wilcoxon signed rank sum test for paired observations, as part of the inferential analysis, is presented in Table 5.6.

Table 5.6

Results of Non-parametric Wilcoxon Signed Rank Sum Test for Paired Observations: Between Group Comparisons

Scale and Subscale	Median		Range		Standardized Test Statistic Z-value	*p*-value
	Family members	Patients	Family members	Patients		
FSS: Cohesion	37	34	1-94	1-94	1.112	0.266
Adaptability	73	58.23	34-94	19-94	1.138	0.255
Total	**52**	**40**	**1-94**	**1-91**	**1.295**	**0.195**
FFS: Family Identity	27	22	18-32	12-28	1.767	0.077
Information Sharing	12	11	9-16	3-14	1.368	0.171
Coping	39	32	27-44	22-43	1.570	0.116
Total	**79**	**66**	**55-91**	**37-84**	**1.853**	**0.064**
FHI: Total	**66**	**62**	**54-70**	**39-74**	**-1.224**	**0.221**
FAD: Problem Solving	1.80	2.20	1.20-2.40	1.40-3.20	1.517	0.013*
Communication	2.00	2.17	1.50-2.83	1.67-3.83	1.484	0.138
Roles	2.38	2.50	1.75-3.00	2.13-3.25	1.142	0.254
Affective Responsiveness	2.17	2.50	1.50-2.83	1.67-3.33	1.688	0.091
Affective Involvement	2.00	2.29	1.29-2.86	1.71-2.86	1.368	0.171
Behaviour Control	1.67	1.89	1.11-2.11	1.22-2.89	1.896	0.058
General Functioning	1.75	2.17	1.25-2.58	1.42-2.92	1.139	0.255

Note. *$p \leq 0.05$.

No significant differences in total family satisfaction, function, hardiness, and general psychological functioning are shown in Table 5.6. A significant difference was indicated on the problem solving subscale of the FAD (p=0.013).

The sample was too small to calculate a meaningful Cronbach alpha score. All the scales used had been standardized and tested previously.

A summary of the **family process profiles,** and differences between patients and family members as defined by the researcher in this study are presented in Table 5.7.

Table 5.7:

Family Process Profiles and Differences Between Patients and Family Members

Process profiles of patients	Process profiles of family members
- Patients and family members do not significantly differ in the reporting of family satisfaction, functioning, hardiness and general functioning - For the problem solving subscale of the FAD the p-value = 0.013 indicated that the patients experienced to have better problem solving skills than the family members.	- Family members and patients do not significantly differ in the reporting of family satisfaction, functioning, hardiness and general functioning

Knowledge of differences may assist in shedding light on the family process profiles reported by the patient and family members and to determine the possible differences between the profiles. Although not part of the scope of this study, this may later assist therapists in designing meaningful treatments that address these issues (refer to 5.2.2.1).

5.2 Qualitative Findings

Qualitative findings regarding the qualitative data gathered are subsequently described.

5.2.1 Description of Qualitative Data

The researcher held interviews and administered the Graphic Family Sculptings (GFS) with members of 15 participating families. In this section, the themes that emerged in relation to the following are elucidated:

- Interviews with families: The researcher used thematic analysis as a method of analysis (Creswell, 2014; Imran & Yusoff, 2015; Willig, 2013).
- The Graphic Family Sculptings: The researcher performed the analysis according to the guidelines of the GFS (Venter, 1993, 2014; Venter et al., 2002).

A summary of the participating family members is presented in Table 5.8.

Table 5.8

Summary of Participants per Family

	Patient	Father	Mother	Sibling	Stepfather
Family 1	X		X		
Family 2	X	X			
Family 3			X		
Family 4	X		X		
Family 5	X		X		X
Family 6	X		X		
Family 7	X		X	X	
Family 8			X		
Family 9	X	X	X	X	
Family 10	X		X		
Family 11	X		X		X
Family 12	X		X		
Family 13			X		
Family 14	X			X (2)	
Family 15	X				

5.2.2 Brief Description of Each Family Interview Based on Field Notes

- **Family 1.**

Only the patient and his mother attended the interview. The patient's mother took the role of the primary caregiver. It is possible that this role comes more naturally to her because of her profession; the entire family relies on her because of that. The patient's mother appeared to be keener to participate in the study than the patient did. The patient relied a lot on his mother's guidance throughout the interview. At times, he tried to voice his own opinion; however, it appeared as though his mother did not allow him enough space to do so. The family presented as if they were confident in handling the diagnosis of epilepsy and that, because the patient is on effective anti-epileptic medication, the seizures (and the impact of epilepsy) is under control.

- **Family 2.**

The patient and her father attended. The atmosphere between them was light and comfortable. The patient challenged her dad in a playful way. Both the patient and her father commented negatively on the absence of the mother in their lives. The family experienced quite a traumatic beginning with the diagnosis of epilepsy and consulted people from many different disciplines to get to the right diagnosis.

- **Family 3.**

The patient's mother appeared to take her role and responsibility as the carer of the family very seriously. The mother copes by investigating different options, consulting different types of doctors, trying different medication options for the patient and being flexible in her approach. She uses different support structures: the patient's school, friends, teachers, doctors, and psychologists. The patient's mother said that her religion is her "anchor." The mother seems to be a fighter, chooses not to be a victim of her own difficult circumstances and teaches her children that they also have a choice. [The researcher wondered whether this family would cope if the mother was no longer able to fulfil this role].

- **Family 4.**

The mother took the lead role in answering the questions and participating. The patient looked very uninterested during the interview and grinned at times when it was not appropriate in relation to the content that her mother had shared. In general, the patient appeared rather unconcerned about the epilepsy and the researcher wondered about possible secondary gain that maintains the pattern because it may suit everyone in the family. The patient, took a passive role and relied on her mother's help and sharing during the interview. The patient said that she just "carries on as normal" as they "cannot do anything about it." She also did not respond with concern when challenged that it appeared that most others with a diagnosis of epilepsy had difficulty in coping. The mother's need to talk about the process of finding a diagnosis, various doctors who they had consulted, the various advice that they had received and the subsequent frustration because they did not have a complete answer yet was evident. At the time of the interview, the patient was not taking any anti-epileptic medication. The mother shared, “Her brother feels that he misses out because he cannot go to the doctor so many times.”

- **Family 5.**

The mother took the lead role in answering the questions and participating during the interview. It looked as though the stepfather is very involved with the patient and sees it as his role to promote some structure and discipline in the patient’s life. The patient’s mother appeared to have a large need to talk about the patient’s epilepsy and the family’s experience. The interview gave the patient’s stepfather much insight into the process in their family in relation to epilepsy. It appeared as though the stepfather does not want to get too involved, particularly with the patient’s epilepsy; possibly because he feels unsure. The researcher perceived that the patient experiences this as an immense loss. The patient’s body language towards his stepfather gave the researcher the impression that the patient actually needs his stepfather to be involved. The researcher perceived the patient’s mother to be the anchor of the family and the one who takes the main responsibility. Initially, the patient was very shy, but made better eye contact as the interview progressed. This family does many things together as a family even during difficult times. The mother indicated after the completion of the questionnaires that she thought they might be in need of psychotherapy at a later stage.

- **Family 6.**

Only the mother and the patient attended the interview. The patient’s father spends time away from home due to work obligations most of the time. This is part of the mother’s difficulty in coping with what she feels has to be “the mother and the father.” The mother took the lead role in answering the questions and participating during the interview. The patient looked irritated with her mother at times. The patient gave the impression that she is accustomed to being the centre of attention. The patient looked self-confident, emotionally strong and gave the impression she was coping. The mother positioned herself toward the patient as if this was “their thing” and possibly it was something that bound them together. The mother and patient coped by gaining a great deal of information by reading, consulting resources and trying to continue life as normally as possible. It looked as if the mother coped by zooming into the patient’s situation and excluding the extended family. The mother and patient have good support structures in place. The patient and her mother consulted different specialists and tried different treatments.

- **Family 7.**

The mother, patient and the patient’s sister participated in the study. The mother feels that she knows her daughters well and answered on their behalf. The two daughters experience a great deal of conflict between themselves and often compete with one another. The mother took the lead role in answering the questions and the patient's sister tried to get and maintain the attention throughout the interview. At times, the patient became emotional and looked very frustrated with her sister who tried to receive the attention. The mother was very keen from the start to participate in the study and felt that "any help" would be very helpful to them. The mother said that she always had been the breadwinner of the family. The mother said that the school is supportive and the patient's favourite teacher hugs the patient when she has a seizure at school.

- **Family 8.**

Only the mother attended the interview. The patient has a younger sister. The father has not lived with the family for some time now. The mother does not work and has been at home with the patient since the patient's birth. The mother was keen to talk about her experience. The mother has experienced a significant emotional load since her daughter's intervention with epilepsy approximately two months ago. The mother looked calm and relaxed, but it sounded as though she had absorbed a lot of stress. The family sought "long and far for answers" and got different medical opinions, tested various medications and was "relieved" to find treatment that worked. The mother said that it helped them to talk to other patients and families in similar situations. The mother is in need of information about epilepsy, the management thereof and coping with it.

- **Family 9.**

The patient, his father, mother and younger sibling attended the interview. The mother is a strong figure in the family and the researcher perceived she holds the family together. The mother was experienced as very calm and relaxed [at some point the researcher felt that perhaps this was 'too good to be true' under the circumstances]. Later during the interview, the mother became quite emotional and cried when she said she feels traumatized about the seizures that the patient had when he was younger. It looked as if the patient was not concerned about anything. The researcher thought that the patient had a disconcerting attitude and 'threw his weight around' during the family interview. The patient's younger brother has taken a lot of emotional responsibility on himself to make sure that the patient is "okay." The researcher felt that the brother could benefit from psychotherapy as well as the parents to help them gain emotional insight about the role and burden of the brother. The researcher discussed this with the parents.

- **Family 10.**

The patient and mother attended the interview. The mother took the lead role in answering the questions and participating during the interview. The patient participated well and at the end of the interview, gave feedback that the interview was valuable to her. The researcher got the impression that the mother and patient support each other and that the father and other sibling are more distant. The father and the brother did not want to attend the interview and does not want to have anything to do regarding epilepsy. It seems that the diagnosis of epilepsy caused some marital strain and strain on the interactions between siblings.

- **Family 11.**

The patient, his mother and stepfather attended the interview. His stepfather made it clear that he was only there in a supportive role. The mother took the lead role in answering the questions and participating during the interview. The stepfather was quieter and more passive. The patient looked irritated at times and did not appear very keen to participate. The mother seemed to be the one in the family who understood the patient's condition the best and does everything in her means to get and give the best treatment and help to the patient. The mother shared that the patient had difficulty studying, and attended many extra lessons. The researcher thought that perhaps the patient was more depressed than both him and his mother realised. The stepfather experiences the epilepsy as a "problem." The mother tried throughout the interview to get some support from the researcher to reinforce her ideas of what she believes the patient must do or change such as studying harder. The patient had a don't-care attitude throughout the interview. The researcher got the impression that the mother feels burdened by everything with which she has to cope. The researcher suggested they be referred to a psychologist for psychotherapy.

- **Family 12.**

The patient and mother participated in the research. The patient's father had started a new job after not working for a long time. The patient had to help her mother a lot to complete the questionnaire. It was a more concrete interview as the mother and patient did not appear to have good emotional insight. It was not so easy to get the participants to elaborate on their experiences. The researcher had to prompt them with questions to get an idea of their experience and coping. The researcher got the feeling that the participants were not very much in touch with their emotional experiences in relation to epilepsy. Furthermore, the researcher perceived that possibly their emotional 'library' in general was limited.

- **Family 13.**

Only the mother participated in the research. The researcher experienced the mother as open, approachable and a strong support to the family who buffers a lot of pain for the family. She herself struggles with medical challenges, but feels that she cannot pay attention to this now. She says she tries to read a lot about epilepsy and gathers information about epilepsy. It appeared as though the caring role regarding her son's epilepsy belongs to her.

The researcher was under the impression that the mother possibly has some bottled-up emotions as she became tearful at different times during the interview. The mother stated that her religion plays an important role in her life. She cried several times during the interview and said that it is difficult to look after her own emotional needs.

- **Family 14.**

The patient and her two sisters participated in the interview. It was clear that the patient has the closest relationship with her middle sister. Her other sister stated that she does not have a good relationship with the other two sisters, but that "it was getting better." It seemed that the one sister took the responsibility for the management and support regarding the epilepsy.

- **Family 15.**

Only the patient attended the interview. Both his parents planned to be part of the interview, but because of unforeseen circumstances they could not. The patient appeared to function independently and it was possibly for this reason that his father felt comfortable that the interview could be conducted with the patient only. The researcher considered that this was a comment on their roles in the family and that the patient appeared to function independently regarding the management of his epilepsy diagnosis as well.

5.2.3 Description of Thematic Analysis of the Interviews With 15 Families as a Group With the Focus on Main Overarching Themes, Sub-themes and Codes

A detailed description and summary of the thematic analysis of each interview with each participating family can be found in Appendix R. A detailed description and summary of the thematic analysis of interviews with 15 families as a group were compiled. Codes were identified and grouped together to form sub-themes. Sub-themes are the themes that occurred in most or more than one family, or themes that the researcher deemed relevant in terms of the research question, even if it only emerged in one family (Creswell, 2014; Imran & Yusoff, 2015). The sub-themes were grouped together to form overarching themes. The overarching themes are related to the research question. The researcher compared these themes to the quantitative results for the group. The details of the sub-themes derived from all the interviews and subsequent codes can be found in Appendix T.

The overarching themes, sub-themes and codes are subsequently described. Some of the sub-themes and codes occurred more than once in certain themes. In such cases, the detail of the sub-themes and codes are provided once, with the first occurrence. However, first, a summary of the thematic scheme is illustrated in Figure 5.2. A summary of the main overarching themes and sub-themes are depicted in this figure. Second, the codes from which the researcher formed sub-themes and themes are presented in Table 5.9. Thereafter, a description of the themes, with verbatim quotations from the interviews, follows. The verbatim quotations are in italics.

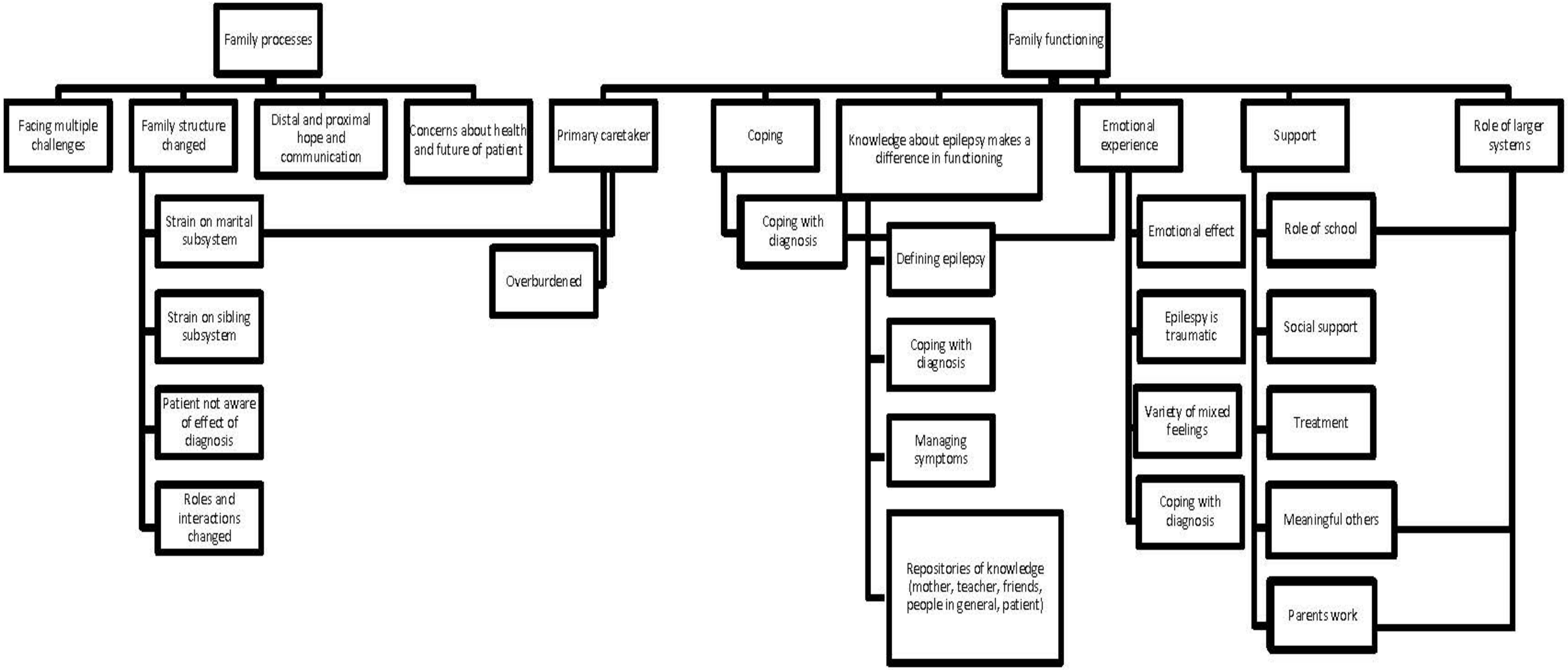


Figure 5.2. Thematic scheme of main overarching themes and sub-themes

Table 5.9

Codes Linked to Themes and Sub-themes

Themes	Subthemes	Codes	
Facing multiple challenges	Developmental challenges Acquired challenges	-Normal adolescent challenges -Patients face other medical and emotional challenges -Parents face own medical and emotional challenges	-Siblings face own emotional and medical challenges
Family structure changed	Roles and interaction changed	-System of families shifted -Complex family processes	-Effect on roles, relationships, interactions
	Strain on marital sub-system	-Strain on marital relationship -Fathers struggle to cope	-Mother primary caregiver
	Strain on sibling sub-system	-Mother primary caregiver -Parental child -Own challenges to deal with	-Different treatment of siblings by parents -Fathers struggle to cope -Sibling rivalry
	Patient not aware of effect of diagnosis	-Patient not aware of effect of diagnosis -Patients do not take responsibility	-Mother primary caregiver
Distal and proximal hope and communication	Hope	-Hope to outgrow epilepsy -Hope that others manage with diagnosis	-Took a long time to get the right diagnosis
	Communication	-Talk about stress	-Involve patient in communication
Concerns about health and future of patient	Concerns about health and safety	-Concerns about side-effects of medication -Primary caregivers are perceived by other family members as overprotective	-Try to avoid triggers
	Concerns about the future	-Concerns about patient's safety -Primary caregivers are perceived by other family members as overprotective	-Concerns about patient's future
Primary caregiver	Strain on marital sub-system	-Strain on marital relationship	
	Primary caregivers overburdened	Guilt feelings -Stressed -Professional support	-Poor quality of life -Need for constructive outlet or need to talk about effect -Carrying a large amount of responsibility

Coping	Coping with the diagnosis	-Continue life as normal -Humour -Struggle to cope	-Healthy balanced lifestyle -Can abuse the situation
Knowledge about epilepsy makes a difference in functioning	Defining epilepsy	-How patient and family members experience or view epilepsy	
	Coping with diagnosis	-Stigma -Struggle with diagnosis	-Healthy balanced lifestyle -Need for constructive outlet or need to talk about effect
	Managing symptoms	-Continue life as normal -Focus on religion -Humour	-Avoid the situation -Healthy balanced lifestyle
	Repositories of knowledge (mother, teacher, friends, people in general, patient)	-Family members in need of knowledge -Empower caretakers with knowledge -Previous exposure to epilepsy -Need of some primary care takers to empower others	-People in general not enough knowledge regarding epilepsy -Other family members diagnosed with epilepsy -Meaningful others lack insight and knowledge
Emotional experience	Coping with diagnosis	-Continue life as normal -Focus on religion -Humour -Struggle with diagnosis -Encourage each other to talk -Took a long time to get the right diagnosis -Stigma	-Avoid the situation -Healthy balanced lifestyle -Can abuse the situation -Need for constructive outlet/need to talk about effect -Keep diagnosis a secret -Do not want to talk about experience
	Emotional effect	-Large impact on family -Guilt feelings	-Affects all family members -Do not want to talk about experience
	Epilepsy is traumatic	-Need to talk about first seizure -Took a long time to get right diagnosis	-Intense medical intervention -Diagnosis is traumatic
	Variety of mixed feelings	-Depression -Anxiety -Frustration -Negative reaction from peers -Stress	-Uncertainty -Anger -Rejection -Experience losses

Support	Role of school	-Support makes meaningful positive difference -Some schools not supportive -Negative impact on schoolwork, peers, patient's self-esteem	-School specifically for epilepsy -Primary caregiver good relationship and communication with school
	Social support	-Stigma -Good relationships with meaningful others	-Some not receive different treatment -Interaction with others in similar situation supports positively
	Treatment	-Support and reaction from treating professionals -Compliance and use of right medication -Researcher recommended psychotherapy -Receive professional support	-Some neurologists do not inform enough -Received hospital treatment -Positive change took place during session although not part of research
	Meaningful others	Their support is important for overall functioning -Lack insight and knowledge -Friends that support	-Also need support and to be empowered -Lack of good communication
	Parents work	-Lack of support	
Role of larger systems	Role of school	-Support makes meaningful positive difference -Some schools not supportive -Negative impact on schoolwork, peers, patient's self-esteem	-School specifically for epilepsy -Primary caregiver good relationship and communication with school
	Meaningful others	-Their support is important for overall functioning -Lack insight and knowledge -Friends that support	-Also need support and to be empowered -Lack of good communication
	Parents work	-Lack of support	

5.2.3.1 Theme: Facing multiple challenges.

The patients and family members faced many challenges that were related and unrelated to the diagnosis of epilepsy. Furthermore, they had to find a way to deal with the diagnosis of epilepsy together with all their other challenges. Developmental and acquired challenges were two major categories with which they had to deal.

- ***Developmental challenges.***

Normal adolescent challenges that adolescents and families have to deal with during adolescence appeared to be apparent.

It is a very demoralizing illness, especially with a teenager. I specifically feel it is the worst time to get this (epilepsy), because you are then building your image, molding yourself (mother of Family 7).

- ***Acquired challenges.***

Not only were the patients faced with the challenge of adjusting to their diagnosis of epilepsy, but they encountered other medical and emotional challenges too.

He (patient) was very difficult to raise…he was very sickly… I stress every winter, as he (patient) does not have good lungs (mother of Family 5).

She (patient) took a lot of opposition in primary school because of being bullied (mother of Family 6).

My heart problem is bigger than the epilepsy (patient of Family 15).

This has an impact gynaecological, sport, long- and short-term memory, appetite, emotional, physical. You do not only treat the diagnosis but at the end of the day, other things are added, psychiatric, gynaecological…so from one thing called seizures so many other tasks are added. It has a big financial impact and her (patient) as she feels useless (mother of Family 3).

His (patient's) self-esteem is a big issue… There are many signs of depression for a long time already. He sleeps a lot, is down, everything is trouble… We spend a lot of time in therapy, play therapy, and courses. He (patient) was in a school for children with special needs… He received special medication, nutrients, and a special diet... He has ADHD and low muscle tone (mother of Family 11).

He (patient) has attention deficit… He had a CT scan when he was six weeks old... He got the tumour in his mouth on the same side a year after that… They had to cut away half of his jaw to cut out the tumour … The chemo did not work… Before he received a diagnosis of epilepsy, doctors suspected brain cancer… (We went from) the one doctor to the other and one professor to the other. It was very traumatic… He (patient) is (emotionally) a year behind (mother of Family 13).

Not only did the parents have to adjust to their adolescent child's diagnosis of epilepsy, but also had to face their own medical and emotional challenges.

Our family went through a lot. My eldest daughter tried to commit suicide five times. My youngest daughter is a medical miracle (mother of Family 3).

I feel that she already has a burden to carry. She had trauma and her behaviour showed that (mother of Family 10).

His (patient's) father passed away then he was 12 years old and it affected him a lot (mother of Family 11).

Even the siblings encountered their own medical and emotional challenges that were not related to epilepsy.

The mother's reaction was *do we need to go to the doctor AGAIN,* as the patient and her sisters need to visit doctors regularly because of their different conditions (middle sister of Family 14).

5.2.3.2 Theme: Family structure changed.

It appeared the diagnosis of epilepsy affected the various roles of family members and the interactions between family members changed. There appeared to be strain on the marital and sibling subsystems. Furthermore, the patients seemed to be unaware of the effect of the diagnosis.

- ***Roles and interactions changed.***

There appeared to be an effect on parental systems and the functioning of families in that in many of the families, the system of the family shifted; in particular, the roles and relationships changed in the family.

Before, I could be a father because there was no condition. Now there is an excusable condition. Ido not want to be the educational father any more. I want to be the supportive father (stepfather of Family 5).

It affects our family life. We spoil her (patient) a lot because she is sick (father of Family 2).

One of the advantages of being sick is that I got closer to my daddy (patient of Family 2).

A bond formed between us while he (patient) was so sick in hospital and when I spent so many hours with him. I realized that I missed so much when he was younger (mother of Family 5).

In Family 6, it appeared as though the patient acted as a mediator to help the father and mother to cope with her diagnosis of epilepsy; the patient, in essence, was part of a triangle.

I think that he (father) can see that I am fine, and when I am fine, he is fine (patient of Family 6).

It appeared as though interactions were affected. Furthermore, confusion regarding roles and expectations in relationships ensued. Some of the siblings became more overprotective of their patients, experienced stress and perhaps became confused about how they could react towards the patients.

The whole situation is annoying. What am I supposed to do? I am 15 years old and you (patient) are supposed to be the older one (sister of Family 7).

My brother feels sorry for me when I have a seizure (patient of Family 14).

My brother (two years younger than patient) worries a lot when I make any movement. He thinks that it is a seizure. That upsets me a little because he makes me to feel bad. He was always the one to fight with me but he is now the one who worries the most (patient of Family 15).

Complex family processes including role confusion, multiple trauma and difficult situations with which to deal, were present. Some families (families 2, 3, 4, 5, 6, 7, 8, 10, 11) experienced unresolved conflict and were in need of conflict management. In some families, there seemed be a further need to redefine roles, acquire constructive coping skills and be referred to psychotherapy.

He (patient) vents on his mother... I must then choose between her (mother) and him (patient) and he (patient) must choose between her (mother) and me (stepfather). She (mother) is overprotective. I am the peacemaker (stepfather of Family 5).

Her (patient) sister was adopted first and then her. Then she (patient) was the golden girl and I think she (sister) was carrying a bit of that (mother of Family 7).

The mother of Family 6 wanted herself and the patient to treat the epilepsy exclusively. Furthermore, the researcher got the impression that the mother hoped this would possibly strengthen her relationship with the patient.

For us it is our thing. We dealt with it (mother of Family 6).

- ***Strain on marital sub-system.***

Many of the participants indicated that their marital relationship was strained. Some parents acknowledged that they were always watching to see if the patient would have a seizure. This affected their own roles and their relationship with the other parent. It appeared as though there was only one family where the parents really supported each other in managing the patient’s epilepsy.

It puts a big weight between us (mother of Family 3).

It frustrates me endlessly that she (mother) does not want to go anywhere and just wants to be with the patient (stepfather of Family 5).

At some stage, we considered a divorce, but I decided to stay (mother of Family 10).

In many of the families, the mother had taken up the role of primary caregiver. The mother got very involved in the caregiving process. However, both the mothers and fathers experienced much frustration.

> *It frustrates me endlessly that she (mother) does not want to go anywhere and just wants to be with the patient… It is easier for me not to get involved with his condition. I want her (mother) to fight that fight. I do not want to get too involved* (stepfather of Family 5).

> *He (father) does not really experience the epilepsy and is not very much involved* (mother of Family 8).

Approximately half of the fathers struggled to cope with the diagnosis of epilepsy and experienced complex losses as a result of other difficulties in life (in families 2, 3, 5, 9, 10, 11, 13, and 15).

> *I once witnessed someone having a seizure and it upset me. I heard that you should stay away from them (epileptics) as they get as strong as an ox. Do not fight a lost war. I cannot handle that condition. I cannot handle it emotionally or psychologically. I do not stand apathetic but I do stand back. I moved the seizures like a black whole away. You give recognition to the fact of the seizures happening and you try to move on* (stepfather of Family 5).

> *His (patient's) father does not always understand. My husband is an ostrich who hides his head under the ground. He just carries on. I want to understand what I deal with but he does not want to hear anything. I told my husband that he must be lenient regarding his (patient's) academic marks, but my husband said it was nonsense* (mother of Family 13).

- ***Strain on siblinh sub-system.***

Many parents treated their other children differently. It appeared as though the patients received more attention than their siblings. This had an effect on the sibling system and the relationships between the siblings. However, some of the parents believed that they treated all their children the same.

> *She (mother) was a tyrant of a mother. However, she is different now. Previously she would yell, but she is much more allowing now* (stepfather of Family 5).

> *He (father) does not treat her (patient) any different from before* (mother of Family 6).

> *We spoil her (patient) a lot because she is sick* (father of Family 2).

> *One of the advantages of being sick was that I got closer to my daddy* (patient of Family 2).

The different treatment had a negative effect on the interactions and relationships that the siblings had with each other and on how the sibling sub-system functioned.

> *It feels as if my sister abandoned me* (patient of Family 2).

When she (patient) gets a seizure, she gets some attention (eldest sister of Family 14).

I know I cannot pep him up and put him in cotton wool… His brother is one year older… It must be fair, although his brother is an achiever… I have a soft spot for him (patient) because he went through everything… I feel so guilty, when I have to take my son (patient) to the specialist, he has had to be admitted many times in hospital immediately, then I had to phone a friend to pick up his brother at school… Then he (brother of patient) was like my foster child as my attention always had to be here (with the patient) (mother of Family 13).

In some of the families (families 9, 13 and 14), there was a parental child that took some emotional responsibility for the wellbeing of the patient and family.

I will turn him (patient) on his side, then I stay with him and it helps me to calm down. When he plays (computer) games, I will always be with him. At times, it feels to me as if I must take care of my brother. It is bad because he is sometimes nasty to me, but he is my brother (brother of Family 9).

In Family 14, the patient and her sisters seemed to shoulder a great deal of responsibility. The one sibling in families 13 and 14 behaved like an overly concerned parent.

It is difficult for me to accept her (patient's) epilepsy. It affects my own concentration and schoolwork. The third seizure was the worst. It was very long and she turned purple in her face (middle sister of Family 14).

His brother is very protective over him. My older son is always there for his brother. His brother is concerned about him and always wants to know where he is and how he is. His older brother is very mature... I think everything has made the eldest son grow up quickly (mother of Family 13).

Some of the siblings had their own challenges to deal with; separate from those of the patients' epilepsy.

They are like twins except they have very different personalities. For practical reasons I did not want them to be in different school years… Her (patient) sister was adopted first and then her. Then she (patient) was the golden girl and I think she (sister) was carrying a bit of that (mother of Family 7).

Almost half of the participants indicated that sibling rivalry was exceptionally high.

At this stage, they (patient and sister) bump heads (mother of Family 8).

She (patient) and her sister have many fights but when she has a seizure, her sister stresses a lot (mother of Family 12).

We do not get along very well at the time, because personalities differ a lot (eldest sister of Family 14).

They do have sibling rivalry but my older son is always there for his brother… They are in the same school. I gave my youngest son a choice but he wanted to follow his brother… He cannot make his own choices and it bothers me (mother of Family 13).

- ***Patient appears unaware of effect of diagnosis.***

The majority of the participants indicated that the patients were unaware of the effect of the diagnosis. It appeared as though the patients were ignoring the fact that epilepsy affected their lives and they seemed to be less concerned than others are about their diagnosis.

I do not think that it will have an emotional and physical impact on me… I was very chilled out through all of this. I was very calm… I am very sure that it affects you (mother) more than me. I am very mellowabout this (patient of Family 6).

I just carry on with life. I accepted it (patient of Family 11).

It (epilepsy) does not bother me any more these days, as long as I drink my pills... (patient of Family 15).

It is possible that this had an effect on the roles, relationships and interactions between family members because the patients did not seem to take responsibility for tasks for which they were responsible. This may be related to the developmental stage of adolescence: adolescents want and need to become more independent and form their own identity. Furthermore, some of the patients did not want to talk about epilepsy.

She (patient) is lazy at times (mother of Family 4).

The wrong type of patient can abuse epilepsy. Someone with epilepsy can be a fantastic manipulator…gain benefits…they are victims and the world owes them (stepfather of Family 5).

He is always scared to commit. Last year I asked him if I can take him to someone he could talk to as he does not want to speak to me (about how he feels)… (mother of Family 13).

5.2.3.3 Theme: Distal and proximal hope and communication.

Hope, in the sense that families hoped that the epilepsy would go away or get better and how families communicated with each other in relation to the epilepsy appeared to play a specific role in how the families dealt with epilepsy.

- ***Hope.***

Some of the families hoped that the patients would still outgrow their epilepsy and this instilled hope in them to cope with their current diagnosis.

It (epilepsy) will stabilize (mother of Family 6).

It was important for him (patient) to learn that he previously got better from it (mother of Family 11).

It took most of the families some time to get the right diagnosis, which contributed to the intensity of their experience. It is possible that this added to their trauma, and influenced their functioning and hopes to obtain a diagnosis and effective treatment.

During 2014, we consulted with her current neurologist who, for the first time, confirmed that she has epilepsy. The neurologist told us then for the first time that it is not witchcraft (father of Family 2).

We went from doctor to doctor, neurologist to neurologist, while she had almost 15 seizures per day. We went to a gastro-entrologist, endocrinologist, physician, two gynaecologists, three neurologists, eye specialist, and endocrinologist to get an answer. We performed different tests, including brain scans. The only one left now was the sangoma (traditional African healer). We were at the best of the best and consulted with any possible doctor that they referred us to (mother of Family 4).

The fact that some took a long time to obtain the right diagnosis might have had a significant effect on their trust in themselves, the medical support, and the treating staff members and support systems. It is possible that some lost hope in ever being in a better situation.

The first year of treatment was unsuccessful as the seizures still occurred and the medication did not make any difference (mother of Family 8).

We had no idea what was going on. We even considered witchcraft, we believe in that. We searched for advice. We consulted a psychologist who told us that there was nothing wrong with her (father of Family 2).

The process to get a diagnosis was very traumatic. He (patient) underwent extensive medical tests like an MRI scan. It was very traumatic for him. It was difficult to find a neuro-surgeon who sees children of that age and most of them have long waiting lists. They admitted him in the intensive care unit among adults who looked very bad for a 36-hour video EEG monitoring to get clarity regarding the diagnosis (mother of Family 13).

Knowing that others manage to cope with epilepsy brought hope to the epilepsy sufferers and their families.

A big cricket player, Jonty Rhodes, has epilepsy but manages it well (stepfather of Family 11).

- ***Communication.***

Whereas some families did not talk about the stress that epilepsy brought, others spoke about it.

We do not discuss it (epilepsy) as a topic (between father and mother), (mother of Family 3).

The family copes by helping each other. I invite the children to participate, sit down and discuss, talk and communicate and share ideas (mother of Family 1).

It helps me to be able to talk about other stressful experiences in life….I consult with a psychiatrist (patient of Family 6).

Many of the families involved the patients in the communication and process of managing the epilepsy; their experience of involving the patients was that it helped them to adjust to the situation.

I do not want him (patient) to feel left out... We always take him with (to the doctor) and he was present in the discussion. I do not want to hide things from him, so he was in each conversation (with the doctor). When we are at the doctor, he cut himself off completely. He just looked down and closed himself off in his own world. My child is a closed book (regarding his emotions). We keep everything open in our house and talk about everything. The only thing we try to hide from my son is me and my husbands' pain because of his epilepsy. We hide our fears from him and cry when he is not around (mother of Family 13).

This was in sharp contrast to what she shared, namely, that she and her husband did not really talk about their son's epilepsy.

It is a taboo to talk about the epilepsy (mother of Family 13).

5.2.3.4 Theme: Concerns about health and future of patient.

In most of the families, the primary caregivers indicated their concerns about the health and safety, and future of the patients.

- ***Concerns about health and safety.***

Many of the participants expressed concern about the side-effects of their particular patient's medication.

I am concerned about the side-effects of the anti-epileptic medication that was prescribed to her in a stronger dosage this time (father of Family 2).

I witnessed a personality change with her (patient) since she started to use the medication. Suppression of her personality occurs when she is on medication… It seems that you will not get rid of this medication (mother of Family 8).

It is a difficult decision. Her chances are 2% to fall pregnant. We will make this choice and will test it to see what becomes of it. Her gynaecologist recommends that she use another type of birth control that does not involve medication. We want to give her the opportunity to be a mother one day and not to take the opportunity away because of the medication (mother of Family 3).

Initially, medication did not effectively prevent the seizures of all the patients (in families 2, 3, 4, 5, 7, 8, 9, 12, 14).

At some point, the patient of Family 12 did not take the recommended medication *as it made me feel dizzier than the epilepsy itself* (patient of Family 12).

Many patients and families tried to avoid known triggers for seizures in an attempt to manage the epilepsy symptoms better. Some were very aware of safety risks for the patients as having seizures could result in a potentially dangerous situation as they could get hurt.

He (patient) must avoid loud noise, and be sensitive to lights. We switch off lights before he enters a room. It is not difficult to assist with this. I took out the key of the bathroom door since his diagnosis. He is alone at home a lot (mother of Family 1).

I cannot get angry or stress any more…I will then talk to myself to calm myself down. When people make me angry I just turn around and walk away (patient of Family 5).

Severe stress may sometimes be a trigger (mother of Family 6).

I must drink a lot of water to hydrate the brain and get lots of sleep (patient of Family 6).

Obviously, I have my limitations. I am not allowed to go anywhere where I have to get the Yellow fever injection or any vaccinations with a live virus. The live virus goes straight through your brain and with the medication it can have a chemical reaction and I will have a more severe reaction on epilepsy and may then have it for life (patient of Family 6).

The neurologist confirmed that it is not good for her (patient) to walk alone. She cannot walk alone and then no one knows where she is when she gets a seizure… Bathing is also an issue… Previously she stayed a lot alone at home. Now I do not like it at all (mother Family 10).

You must stick to the rules that the doctor gives (regarding epilepsy)… Make sure that you sleep at least six hours at night… Someone diagnosed with epilepsy must stay away from alcohol. It is sad but it is better (patient of Family 15).

Almost half of the primary caregivers were perceived by other family members to be overprotective.

She (mother) is overprotective (stepfather of Family 5).

I do not want her (patient) to ride on a bicycle. You do not have control (mother of Family 8).

- ***Concerns about the future.***

Concerns were expressed about the patients' safety when having a seizure so as not to get hurt in such a way that it affected their wellbeing in the future. Concerns about their future also included who would take care of the patients if the primary caregivers were unable to do it anymore in the future.

I am concerned about her safety as she, for example, cannot swim… The seizures never disappeared. A minute is a lot… It is very unsafe for her (patient) to drive… I was angry when I realised how wrong things can turn out and that you can lose her very quickly if there was not someone (to keep an eye) (mother of Family 8).

When she gets a seizure, you have to help her that she does not hurt herself (mother of Family 12).

Although the patients did not explicitly express concerns about their future, some of the primary caregivers had thought about this a great deal.

Will she be able to work? Will she (patient) be able to fall pregnant one day? How will it affect her one day if she decides that she does not want to fall pregnant, how will it affect her husband? It brings a responsibility in a relationship and in a marriage. Perhaps she must not have children. Perhaps she must find out if it is inheritable. What about neurological deterioration, do you need to make plans now already for when she (patient) gets older? Then you realise that is the next thing we need to deal with. You cannot accept that it will work out by itself (mother of Family 8).

Epilepsy closes doors, as when you want to become a pilot. This he does not know but because I work in insurance, I know that as soon as you say epilepsy and prosthesis it will count against you a great deal. Also for one day when he works, even if he does not have epilepsy anymore (mother of Family 13).

5.2.3.5 Theme: Primary caretaker.

In most instances, the patients' mothers were their primary caregivers. Traditional gender roles were evident in many of these families. In the majority of the families, many of the participants perceived that their fathers were uninvolved or played a more passive role in the family, especially in relation to the diagnosis of epilepsy. This strained the marital system as the primary caregivers felt overburdened.

- ***Primary caretaker overburdened.***

A minority of the primary caregivers felt guilty about the seizures. The mother of Family 10 was also diagnosed with epilepsy.

It makes me feel that it is my fault that she got the epilepsy, because of bloodline curses (mother of Family 10).

Almost all the primary caregivers and participating families faced their own challenges, separate from those of epilepsy. Most of the family members perceived their quality of life as poor.

Mommy is always sick (patient of Family 2).

She (mother) said to him (patient) that it was a fault to have him (stepfather of Family 5).

It is not always easy to be 58 years old and to raise a child. He is not an easy child to rise. He builds a wall around him and that is something we need to work on. I sometimes feel that I want to pack my car, leave, and get new number plates and a new card in my cellphone (mother of Family 11).

A number of the primary caregivers experienced stress.

It creates a lot of stress and uncertainty and you do not sleep well. You do not know what is going on. The seizures never disappeared… I handle everything for her (patient). When I am angry or disappointed I do not show it to her. You have to work around it (mother of Family 8).

We can never leave him alone like at a swimming pool. Everywhere he goes we have to go with (father of Family 9).

If he does not answer when we call him, we all jump up and run to see if everything is okay. You get cold (mother of Family 9).

My parents must not immediately think that any strange movement means that I am having a seizure (patient of Family 15).

I will keep on watching him until (he, patient, is) 18 years old (mother of Family 1).

We did not know what to do and it was making me sick… I developed psoriasis because of the tension regarding the epilepsy (father of Family 2).

She needs 24-hour supervision… If I give up my whole family will fall apart… We will not leave her (patient) somewhere and will not be alone (mother of Family 3).

I was completely freaked out. My husband was out of the country and I was dealing with this whole thing. I was a wreck. It was horrible for me. It is huge; it is horrific… that this (epilepsy) happened (mother of Family 6).

My mother does not tell anyone (patient of Family 6).

Her whole lifestyle has changed, my whole lifestyle changed, I worry about her and I do not want her to go out alone… I am with them (patient and sister) every minute of the day… I am the nurturing one and the one that will be there through thick and thin (mother of Family 7).

Most of the primary caregivers appeared to be overburdened and thus, they needed a constructive outlet.

You stop a lot of your life to accommodate the situation… When you have a child with epilepsy, you are 24-hours on watch, even if you sleep. You do not leave the patient, you always tell someone else to keep an eye without her knowing that… Your phone had to be on and if it beeped, you have to look, as it could be her (patient). You are on watch. There must always be someone on the lookout… I was angry when I realised how wrong things can turn out and that you can lose her very quickly if there was not someone (to keep an eye) (mother of Family 8).

There was a need to talk about the effect of the diagnosis and to get help and support for the family members and patients.

He acted like someone who was mad. I did not want it for my child. I always lived with that fear. When I heard a sound, I always asked whether he (biological father of patient) was okay. He (biological father of patient) always had seizures while in the shower, and then you had to try to get a body soaked with soap out of the shower. I never relaxed and only realised it when that life was over (mother of Family 5).

I do not really want to get those kinds of severe seizures…he (father also diagnosed with epilepsy) has pain afterwards, bites his tongue and can't remember things afterwards (patient of Family 5).

It (epilepsy) has a very big effect (mother of Family 7).

When she starts shaking everyone starts freaking out (sister of Family 7).

The researcher recommended professional support for some of the primary caregivers.

I have three children with problems. I have my packages (mother of Family 3).

Some forms of epilepsy cause brain damage and you feel please help me (mother of Family 8).

If you do not realise you have a problem… as soon as you realise you can go for help (mother consults a psychiatrist), and reach out and you can get the help. For me, to cope with the epilepsy, it is important that I also receive support (mother of Family 6).

The primary caregivers also appeared to carry a large amount of responsibility.

Everything comes down me (patient's mother), the admittance (of the patient in hospital), tests being performed, to console her (the patient), to see the doctors, etcetera, so I am used to it (mother of Family 3).

She (mother) does not always cope. She cannot not get away from it (epilepsy) and she takes it too much upon herself. She cannot relax. She does not switch off. I feel she must switch off and I told her many times before… She (mother) does not want to do it any more as she feels too worried about the patient (stepfather of Family 5).

I am bitter because I do not have pleasure and have all the responsibility (mother of Family 5).

Her father works abroad and I was all alone. I am a mom and dad… When you (patient) are a mother you will see how intensely you experience things that happen to your child (mother of Family 6, to patient).

My mom worries (sister of Family 7).

I ask my mom to help me, not my sister, or my brother (patient of Family 7).

The researcher perceived that the mother of Family 13 had possibly bottled up emotions as she cried several times during the interview. She shared that it was difficult to look after her own emotional needs.

Any help is welcome. To me all those things are signs that he struggles a bit, but my husband does not want to hear this and I keep it to myself (mother of Family 13).

5.2.3.6 Theme: Coping.

Coping in the interviews is described in relation to coping with the diagnosis of epilepsy.

- ***Coping with the diagnosis.***

The majority of families tried to continue with their lives as normal or tried to act normal as if nothing had changed.

She wants us to treat her normal and not different as some other children (mother of Family 3).

When he was born, I decided that I would raise him in a normal way (mother of Family 13).

I just carry on as if nothing ever happened. I do not talk about it a lot. I just carry on (patient of Family 6).

You have to just get up and go. You cannot put your head like an ostrich in the sand (mother of Family 6).

The doctor said that we must stop babying her. She must cope with life. We are molding a person here (mother of Family 7).

A few of the families coped with the diagnosis by doing relaxation exercises and following a healthy balanced lifestyle. They also engaged in other activities.

She just centres herself, breathes in and out, sit, and then she carries on (mother of Family 6).

Music and singing helps me to cope. I can express my emotions through this (patient of Family 10).

Some families used humour as way of coping; by doing so, they possibly allowed themselves to reframe some of the difficult impacts into more positive experiences.

We also have some humour (mother of Family 8).

I am privileged that some of the most handsome male teachers and best athletes in my school support and carry me when I have seizures at school (patient of Family 14).

Some families struggled to cope.

No one in our family can actually cope with it. My husband and younger daughter cannot handle this and choose not to talk about this (mother of Family 3).

She (patient) cannot function well…headaches, fever, off balance and then she is two or three days out of the society (mother of Family 4).

It is hard. I struggle. Sometimes the coping is good in the family and sometimes it is bad (patient of Family 7).

I am not coping (mother of Family 8).

I struggle with it (epilepsy). I sleep a lot to try to forget (patient of Family 11).

Family 13 perceived part of their coping being a medical aid that paid for the patient's intensive and expensive treatment. This was to the father's detriment; he was unhappy at work, but remained in his current job because of the medical aid benefits he received.

He (father) is unhappy at work but because of the medical aid, he cannot move work. We need to stay on this medical aid (mother of Family 13).

5.2.3.7 Theme: Knowledge about epilepsy makes a difference in functioning.

A major theme that emerged was that knowledge about epilepsy and coping with epilepsy makes a difference in how families cope with the diagnosis of epilepsy.

- ***Defining epilepsy.***

This sub-theme focused on how the patients and family members experienced or perceived epilepsy. The families stated that there was not enough knowledge about epilepsy; they could not prepare for the diagnosis and needed more information. Most of the families experienced the diagnosis of epilepsy as a surprise.

I was so surprised…nothing happened since he was born (mother of Family 1).

I did not know anything about epilepsy. We do not hear people ever discussing this (epilepsy). Maybe we need more programmes (mother of Family 7).

- ***Coping with diagnosis.***

Some families perceived that there was a stigma attached to epilepsy. This made it more difficult for them to cope with the diagnosis.

I feel, anything else, but not epilepsy for my child, as there is a stigma attached to it and I see other people making jokes about it (mother of Family 5).

You feel embarrassed (sister and mother of Family 7).

He (patient) does not talk about his epilepsy, not at all. He is very shy about it… There is a stigma around it… Maybe… someone said something about it to him… (mother of Family 13).

I am concerned that people will think that I am a freak… I had a seizure at school…, my mother parked with her car on the rugby field to fetch me, and all the schoolchildren were watching to see what was going on… I start to feel labelled (patient of Family 14).

The perceived stigma influenced the epileptic adolescents' interactions with others, especially with their peers.

My whole life changed. I cannot go out with my friends. My sister does not want to be with me, she is too scared that I may have a seizure (patient of Family 2).

She (patient) withdraws to her bedroom… She (patient) feels disabled and not normal (mother of Family 7).

There are friends who support and some see it as sensation (mother of Family 8). *I keep it still* (patient of Family 12).

She does not really mingle…She is known as a nerd at school and does not have a lot of friends, so with the seizures it is sort of under the radar…She does not really want to talk about it. It is a big thing for her… They told her straight that she is weird and that they cannot go out with a freak (mother of Family 3).

I withdraw …feel left out… You feel discriminated against you. I could do it before the time but cannot do it now… They have the audacity to judge me or say I am weird… (patient of Family 7).

Many of the caregivers acknowledged that they did not have sufficient knowledge about epilepsy and the management thereof, and struggled with the diagnosis.

We are still not sure why she gets epilepsy. We are also still uncertain what to look at regarding the epilepsy. If we could know more, it would help (mother of Family 12).

I feel we need education (father of Family 2).

We always ask questions. You equip yourself with as much information as possible (mother of Family 6).

I am afraid what to do when someone has a seizure. It is a scary thing...I feel that doctors do not inform us well enough. They give clinical explanations. What we know we taught ourselves and Googled. What caused this? Did we do something wrong? It is difficult to inform yourself. It is disappointing that only one doctor recommended surgery. If I knew earlier, I would take her much earlier and not exposed her to so much medication and for the difference it could have on her personality… (mother of Family 8).

We did not know what it was. We were stupid, we did not know…I will buy the 'Huisgenoot' (popular local magazine) if there is an article about epilepsy (mother of Family 9).

After each seizure, *everyone in the family is more aware of the epilepsy again for plus minus a month* (middle sister of Family 14).

After each seizure, the middle sister of Family 14 watched the patient and sat with her when she bathed. The patient was not allowed to swim for a while.

Many of participants seemed to have a need for a constructive outlet or a need to talk about the effect epilepsy had on them.

*** *Managing symptoms.***

Part of the coping strategies for some involved trying to avoid the situation.

Perhaps it can be easy to try to forget about the epilepsy, to try to cope and not to put your thoughts too much on that. That is how I cope. Someone must not remind you of the situation the whole time (eldest sister of Family 14).

Many of the families relied on their religion to help them to cope.

We consulted three spiritual leaders as well to try to get answers (father of Family 2).

If I did not have my religion, I would not have been here. My religion anchors me. I turn to the Lord and ask for extra grace (mother of Family 3).

Now I have to learn that the Lord is in control of everything (mother of Family 5).

You should hang in there as the Lord has a plan for everything (patient of Family 12).

One mother stated that other religious people had contributed to her doubts as they had passed upsetting remarks.

There are people, not from our church, who think that it is something demonic. It upset me (mother of Family 10).

- ***Repositories of knowledge (mother, teacher, friends, people in general and patient)).***

More than half of the families felt that people in general, including those at school, friends and family members did not have enough knowledge about epilepsy and were in need of information and knowledge about epilepsy.

Everyone think you have to put your hand in her mouth to catch her tongue…It feels like epilepsy is a stepchild of neurology (mother of Family 8).

The mothers of Families 12 and 13 perceived that she herself did not have enough information on how to deal with epilepsy.

It scared me as I heard someone could get as strong as a cow when she has a seizure and that someone like that can then kill you… When I saw a seizure then for the first time I ran out of the room and did not know what to do… People are uninformed regarding epilepsy and I think that people must know more about epilepsy. Today I know that people do not get so strong that they will kill you (when having a seizure) (mother of Family 12).

I always have to explain nicely that it is not seizures. It is internal and you cannot see it… Children do not understand epilepsy (mother of Family 13).

The primary caregiver's reaction to the first seizure appeared to have a significant effect on the patient and family's reaction and possibly functioning.

Obviously, I have my limitations. I am not allowed to go anywhere where I have to get the Yellow fever injection or any vaccinations with a live virus. The live virus goes straight through your brain and with the medication it can have a chemical reaction and I will have a more severe reaction to epilepsy and may then have it for life (patient of Family 6).

Three of the families had other family members who had also been diagnosed with epilepsy and therefore, had had previous exposure on how to live with it. This, in itself, did not necessarily make it easier for these families to deal with the present diagnosis of epilepsy. Some indicated that having previous exposure to epilepsy was traumatic.

He acted like someone who was mad. I did not want it for my child. I always lived with that fear. When I heard a sound, I always asked whether he (biological father of patient) was okay. He (biological father of patient) always had seizures while in the shower, and then you had to try to get a body soaked with soap out of the shower. I never relaxed (mother of Family 5).

It makes me feel bad (to see others having seizures) as they get hurt. He (father) gets it quite severe…it was not nice (patient of Family 5).

She (patient) was shocked to see others having seizures when she was admitted to hospital for surgery as she never saw herself having a seizure. I was then much more worried that perhaps they could not do anything to help her and now she saw the full picture what it looked like… (mother of Family 8).

He (late husband, diagnosed with epilepsy) was a difficult and aggressive man. My father had severe epilepsy and had a stressful job and everyone had to walk on eggs. It was very traumatic to me I could not invite my friends over as I did not know how my father was, in which mood (mother of Family 11).

The mother of Family 10 also had a diagnosis of epilepsy.

It makes me feel that it is my fault that she got the epilepsy, because of bloodline curses (mother of Family 10).

Significant others lacked insight and knowledge about epilepsy. Furthermore, some families shared that having knowledge about epilepsy supported their meaningful others.

I cannot support him (patient) but I can support her (mother). I am rather the supportive element and help her (mother) so that she can handle the situation… She (mother) must take him (patient) for amilkshake and convey the negative in a positive environment… I heard that you should stay away from them (epileptics) as they get as strong as an ox. Do not fight a lost war. I do not know how to handle it... The training that I received included, leave him and stay away from him, stay at a safe distance and do not interfere (stepfather of Family 5).

I get more support from school than from my family (patient of Family 7). *I want her (patient) to look at reality. People who walked around without a leg will rather have a seizure (than to be without a leg)* (sister of Family 7).

Some of the primary caregivers wanted to empower others with information about coping with epilepsy; maybe sharing would enable them to cope better with the situation. The researcher thought it possible that these primary caregivers wanted to find meaning in their own role within the family. Three primary caregivers (Families 6, 7 and 8) felt strongly about empowering others with information on epilepsy and took an activist role. One took a strong position about the school's obvious lack of understanding.

I believe that she (patient) can give an important testimony to others and help others in this type of situation (mother of Family 3).

I want to become an activist for it and show people that it is not leprosy (mother of Family 7).

I have the need to jump in legally with children's rights (mother of Family 8).

5.2.3.8 Theme: Emotional experience.

Coping with the diagnosis had an emotional effect, was traumatic and allowed families to experience a variety of mixed feelings.

**** Coping with diagnosis.***

Some families encouraged one another to talk about the experience.

My mother does not tell anyone…It helps me to be able to talk about other stressful experiences in life…. I consult with a psychiatrist (patient of Family 6).

Emotionally it is a big thing (but when the researcher asked whether they went for emotional help, they said, never). *We tried tocope with everything ourselves but when we talk about it we cry a lot* (mother of Family 9).

I am always aware of the epilepsy but it is something we have to live with (father of Family 9).

Some families kept the diagnosis a secret from others as advised by their neurologist. It is possible the neurologist suggested this because of previous experience on how others might react towards the patient and because of the stigma attached to epilepsy.

The neurologist advised him (patient) to keep quiet about the diagnosis. Our friends know about his epilepsy and it does not really make a difference (mother of Family 11).

I told one of my teachers (about the epilepsy) and it made me feel better. Most of my friends do not know that I have epilepsy (patient of Family 11).

Some of the families acknowledged that the communication in their families was not good and that they did not talk about epilepsy.

It feels as if my sister abandoned me (patient of Family 2).

Nobody talks about this, not the aunts, the grandparents, but they are all informed (mother of Family 6).

We each process it on our own way (mother of Family 9).

We became very isolated (mother of Family 10).

*** *Emotional effect.***

The diagnosis of epilepsy had a significant emotional impact on the families.

Her (patient's) whole lifestyle has changed, my whole lifestyle changed, I worry about her, and I do not want her to go out alone. The seizures are bad. Her muscles pull back, she bites herself terribly, and I once had to rush her to the emergency room. I never experienced anything like this before. She once said that she would rather die than to have a seizure. The seizures happen on a daily basis (mother of Family 7).

It creates a lot of stress and uncertainty. You do not sleep well. You do not know what is going on (mother of Family 8).

We had to pick up this 'dead' body and put him in the car and take him to hospital. He (brother) was hysterical (mother of Family 9).

Before, life was normal, but there is more stress since the diagnosis of the epilepsy. No one suggested that we should sit down and talk about the epilepsy (father of Family 9).

She (patient) is confused after a seizure. It is very upsetting to us when she does not recognise us (mother of Family 10).

It was very bad for me and he (patient) took very long to get used to it. You must learn to relax. He cannot swim alone anymore. If you make a big issue out of it, you create a hang-up for him. It is a big adjustment and an adjustment at school (mother of Family 11).

When she (patient) has a seizure, it is not pretty (mother of Family 12).

It is very intense for him. It is still difficult for me and still hurts me a lot. I have to take him to the hospital and to the doctor. When he was in ICU, I wanted to pick him up and carry him out. I cried a lot in the parking lot. It was a desert. You cannot talk to anyone. No one knows how you feel. You feel very alone. I cried on my way to work that no one saw me. My husband cannot always support me. I have a friend that supports me. My closest family hurt me the most. My brother phoned me and asked why you scratch where it does not itch. He does not understand the pain that I had to go through and how it hurt when they had to do another test. My family did not understand why I could not visit them. I did not know what would have happened the next day (mother of Family 13).

The fifth (and last seizure) happened when we went shopping. I was alone in a fitting room trying on clothes. I always go shopping alone, but with this one, I thought I was going to die. My sisters rushed to fitting room to help and climbed over the cubicle of the fitting room... I do not want to know what I look like when I have a seizure. I have the worst type of epilepsy, where both brain lobes are involved (patient of Family 14).

All the participating families reported that the epilepsy affected all the family members.

Our whole lives changed. For four years, we have not gone on holiday… We did not know what to do and it was making me sick (father of Family 2).

She (sister of patient) struggles to accept this…She is not coping. This is a very big emotional hurdle for her. She has a lot she has to cope with on a daily basis (mother of Family 3).

Epilepsy has a much bigger affect than for example blood pressure. It affects your whole life (mother of Family 8).

We can never leave him alone like at a swimming pool. Everywhere he goes we have to go with (father of Family 9).

If he does not answer when we call him, we all jump up and run to see if everything is okay. You get cold (mother of Family 9).

This is a lifelong thing to cope with… We all stress about it (epilepsy) (mother of Family 12).

*   ***Epilepsy is traumatic.***

Almost all of the primary caregivers wanted to talk specifically about the first seizure that the patients had.

This thing is a very big traumatic thing. You had a normal child for 14 years and all of a sudden, your whole life turns upside down, in a wink of an eye… You just received it and could not choose. You could not make a decision about it (mother of Family 3).

I was completely freaked out… I was a wreck. It was horrible for me. It is huge; it is horrific… that this (epilepsy) happened. It is huge…and horrific…and the process of finding out what was going on (mother of Family 6).

He (patient) had his first seizure when he was 3 years old. He got red in the face and coughed funny. With the help of the neighbours we rushed him to hospital. I witnessed a seizure and brought him to hospital. It was a big shock (mother of Family 11).

He received the diagnosis of epilepsy two days before he turned ten years old. I remember it very well as I initially thought he had a brain tumor and he had a neurosurgeon and neurologist looking after him. He got headaches. The school phoned, there was something wrong, he did not react. We did not realise this as we always thought that he was a dreamer. His headaches became more severe. The one evening they played PlayStation and all of a sudden, he could not see (mother of Family 13).

Some of the patients also wanted to talk specifically about their first seizure.

I was going blank and ending up at the sister at school. I felt drowsy and confused about what was going on. My mom walked in as if I just had revived from the dead (patient of Family 6*).*

The first seizure happened when I was at a school camp, rehearsing for a concert. I started to spin around and fell on my nose, hurting my nose. My painful nose was the only evidence for the fall. We were not sure at first that it was a seizure. It was a freak accident (patient of Family 14).

Having epilepsy and receiving a diagnosis of epilepsy is an intense medical intervention. The patients underwent many medical tests and had different medical consultations. At times, they consulted different types of medical specialists and were admitted to hospital. The primary caregivers appeared to be very involved in this part of the process and it seemed to traumatize them as it was apparent that they were very involved emotionally.

They did a full assessment on her… It was terrible and very upsetting to me… including MRI- and CAT scan. It took four paramedics and many assistants to calm her down… Medication meant for a man of 120 kg did nothing to her… Her veins collapsed and the paramedics tried 38 times to put on a drip (mother of Family 3).

There were MRIs and everything. I thought, seizures, brain tumor. She consulted another neurologist and was hospitalised for 24 hour video EEG monitoring. The neurologist witnessed a seizure 22 hours into the 24 hours EEG, and then they could pinpoint exactly where it was (mother of Family 6).

Most families experienced the diagnosis of epilepsy as traumatic and spoke about their experience spontaneously. Rather, she got the impression that the families really needed an opportunity to talk about the epilepsy.

It (epilepsy) came by surprise. We did not know what to expect (father of Family 2).

It is not nice. I cannot explain to someone how it feels (patient of Family 7).

We did not know what it was (mother of Family 9).

She had a blackout in the back of my car while I was on my way in peak traffic on a very busy road. The one minute I spoke to her and the next minute, she passed out. We could not get her back. When we got her back after half an hour, she felt disorientated, had no balance, did not know whom she was or where she was, what was happening around her. I had to urgently come to school. There was no time to do other things as they already called the ambulance. I feel like giving up hope if things do not work. So many tests, changing of medication, resuscitated at times. Every admission was very traumatic. This has an impact gynaecological, sport, long-, and short-term memory, appetite, emotional, physical. You do not only treat the diagnosis but at the end of the day, other things are added, psychiatric, gynaecological…so from one thing called seizures so many other tasks are added. It has a big financial impact and her (patient), as she feels useless (mother of Family 3).

- ***Variety of mixed feelings.***

The patient and family members experienced a variety of mixed feelings that included depression, uncertainty, anxiety, fear of feeling out of control, anger, frustration, isolation, rejection, negative reactions from peers, loss and stress.

More than half of the patients isolated themselves and withdrew. Some shared that they experienced symptoms of depression. The researcher also perceived many of the patients experienced symptoms of depression. The researcher recommended professional support for some of the patients.

She (patient) feels like a burden, she tried to commit suicide, received treatment at a psychiatric hospital and she says she is a financial burden and not worth it (mother of Family 3).

She (patient) withdraws to her bedroom (mother of Family 7).

I withdraw …feel left out (patient of Family 7).

I feel depressed (patient of Family 11).

She (patient) sleeps more and turns into herself. She is a lot within herself. To me it feels a lot like a type of autism. She holds back, a big wall to try to protect her… She (patient) struggles to feel or explain emotions. When she gets upset, she will cry or be super overly frustrated (mother of Family 8).

Everyone says it is going to get better, but it is not getting better, when is it going to get better (patient of Family 7).

There are many signs of depression for a long time already. He (patient) sleeps a lot, is down, everything is trouble… You have to have a dream and I see with him (patient) the dream to live lacks. It pulls me down (mother of Family 11).

Most of the families experienced feelings of uncertainty.

It is the closest diagnosis, but still not sure, what type of epilepsy… It is still a very uncertain time…the thing is you do not know exactly where you are (mother of Family 3).

We cannot go on holiday. The last three years was hell (father of Family 2).

We do not move forward at all… If we knew what was going on, we could cope with it, make peace with it, and carry on. The fear of the unknown is not nice (mother of Family 4).

It creates a lot of stress and uncertainty. You do not sleep well and do not know what is going on. The seizures never disappear … You worry (mother of Family 8).

The participants experienced feelings of anxiety and stress.

This is very stressful as my husband thinks that I overreact (mother of Family 10).

Emotionally it creates a lot of strain for her (mother of Family 3).

We (family) are nervous and scared, not relaxed anymore (mother of Family 7). *It is very stressful* (mother of Family 8).

In addition, almost a third of the families had a fear of feeling out of control in an uncontrollable situation.

No one has control over this. It is so difficult to predict so we must take it as it comes when it is there. We received it whether we like it or not (mother of Family 3).

It (epilepsy) is out of your control and it sometimes scares you (mother of Family 5).

To me it feels I must just be in control now (mother of Family 6).

It is a lot of stress for a girl to lose control. You do not know in which situation you lie there on the ground, you are much more exposed and disorientated when you lie there. You do not know what you look like when you get the seizure (mother of Family 8).

A minority of the families experienced feelings of anger and frustration.

I am very cross about the thing (epilepsy) that happened, this monster. I am just fighting this thing (epilepsy). I do not want outside people, it is just me, and this thing and you (epilepsy) will not rule us (mother of Family 6*).*

I also get frustrated (patient of Family 7).

It is frustrating, as we did not get any answers yet… That causes a lot of frustration (mother of Family 4).

Many of the patients experienced rejection or a negative reaction from their peers, which caused the patients to withdraw. This had an effect on their interaction with peers.

My whole life changed. I cannot go out with my friends. My sister does not want to be with me, she is too scared that I may have a seizure… It feels as if my sister abandoned me (patient of Family 2).

They told her straight that she is weird and that they cannot go out with a freak (mother of Family 3).

Almost all the patients experienced complex losses, both various and traumatic losses because of epilepsy.

She (patient) wants the 'old her' back… She wants to study medicine and now all of a sudden she cannot. It smashes your dreams. Her whole lifestyle has changed, my whole lifestyle changed, I worry about her and I do not want her to go out alone (mother of Family 7).

I feel left out because I cannot go to sleepovers… Friends discuss important things there, and I then only find out about it two weeks later (patient of Family 10).

(When having a seizure) *it feels like it stole five minutes from my life* (patient of Family 14).

Epilepsy affected the self-image of some of the patients.

She loves clothes and she loves her hair to look nice… We do not want her (patient) to feel exposed to something like that (epilepsy) (mother of Family 7).

5.2.3.9 Theme: Support.

The major role players who supported the patients included the school, social support, treating professionals, meaningful others and the parents' place of employment.

- ***Role of school.***

Most of the families believed that support from the school made a meaningful positive difference in their coping with epilepsy.

There are teachers on the lookout and who know what to do (mother of Family 3).

This was wonderful as they immediately put things into action (by compiling a support programme for peers about epilepsy, by school psychologist) (mother of Family 6).

The school is supportive (mother of Family 7). *The previous school did not handle it in the right way* (mother of Family 10).

Children do not understand epilepsy (mother of Family 13).

Four of the patients attended a school specifically for children with epilepsy and it had made a meaningful positive difference in their management of their type of epilepsy.

They will call the sister (nurse) at school…but we (schoolchildren) all know what to do (patient of Family 5).

The children are more understanding. They do not think that it (epilepsy) is something funny, where with the previous school, the children did not know it (epilepsy) and it was embarrassing to him (patient) (mother of Family 9).

She (patient) was always unhappy at the previous school and it created stress, and we wanted to stay away from the stress, as it might be a trigger point... I feel safer at the new school… (The school reacted quickly when the patient choked on water once). They are caring and react quickly (mother of Family 10).

We do many extra things to make school easier. He (patient) will not be able to cope in a normal school. The smaller classes at school, only ten children in a class, also help the patient to cope better. I try to assist him in his schoolwork and summarize his schoolwork for him (mother of Family 11).

The children are accommodating with each other… The school gives opportunities to all children… They do not discriminate (mother of Family 13).

Some did not experience the school as being supportive or understanding. Furthermore, they believed the school did not possess enough knowledge to support a child with epilepsy.

School camps and communication regarding her epilepsy are a big frustration. I have many fights with the school. I refuse directly that she goes on school camps… Teachers want her (patient) to carry on and they do not understand what the psychological impact is (mother of Family 8).

Almost half of the primary caregivers had good relationships and communication with the patients' schools. It seemed as though they had initiated the communication with the school for the sake of the patients.

On all forms that I have to fill in at school, I have to say 'epilepsy and prosthesis'… When he goes on a camp, I have to say 'epilepsy and prosthesis' (mother of Family 13)

More than half of the participants stated that epilepsy had a negative impact on the patients' schoolwork and that the seizures they had at school had a negative effect on the patients' self-esteem and their peers.

She does not complete her exam papers (mother of Family 4).

My marks dropped drastically (patient of Family 4). *His academic performance went down* (mother of Family 5).

I stress a lot, as the exams are difficult… Schoolwork is a lot (patient of Family 5).

I cannot keep up (with schoolwork) (patient of Family 7).

It (pressure with schoolwork) is not a good thing at this stage… it takes a toll on her (mother of Family 7).

He has difficulties studying (mother of Family 11).

His marks were always good, in the seventies, but it then fell drastically… I am not sure whether he struggles at school because of the epilepsy. I read a lot about it and see there can be a concentration problem… but also learning problems… To me all those things are signs that he struggles a bit, but my husband does not want to hear this and I keep it to myself (mother of Family 13).

- ***Social support.***

Some did not experience different treatment because of epilepsy. Furthermore, they not feel very affected by the perceived stigma experienced by most.

Nobody treats her (patient) differently. There is no discrimination or pushing her out whatsoever (mother of Family 6).

The patient of Family 15 seemed to cope with his friends and epilepsy. His friends were aware of his epilepsy. When his friends visited, they accommodated the patient by allowing him his sleeping time.

My friends do not act different to me because of epilepsy (patient of Family 15).

Some emphasized good support and good relationships with meaningful others. Some of the families had friends or others that supported them emotionally.

It helps to have a strong support system (patient of Family 14).

Parents must communicate with the patient and ask how she feels about having a seizure. If the patient does not tell how she feels or what her fears are, it will be difficult for her family to support in the right way (eldest sister of Family 14).

It appeared as though interacting with others who were in a similar situation helped many of the patients and families. This was a recurring theme and it may assist with coping.

I believe that she (patient) can give an important testimony to others and help others in this type of situation (mother of Family 3).

It can help to talk to someone who experiences the same type of situation (patient of Family 12).

There were patients at the surgery hospital who wanted to talk about it (epilepsy). To talk was good and very valuable, because you actually do not talk about it. Parents could also talk to each other about their experiences… I rather take our 'package' than to take any of the others… We learned a lot there at the hospital (mother of Family 8).

* *Treatment.*

It was apparent that the reaction and support from medical professionals made a positive difference in their coping. Some of the family members were of the opinion that they needed a primary doctor to help manage the epilepsy. They also believed that the positive relationship with this primary doctor gave them hope and confidence to cope in their own way.

I feel that I want to stick to one doctor (patient of Family 2).

I feel we need someone to put all these things together (mother of Family 4).

The neurologist confirmed that there is nothing wrong with the capacity of her (patient) brain. She can carry on living her life. This will not influence her intellect (mother of Family 6).

This (the approach of the neurologist) is a very positive experience. He is calming. He explains everything very well (mother of Family 10).

Some family members felt that their treating doctors did not inform them enough about the management of epilepsy and that information could make a positive difference in their way of coping.

I feel that doctors do not inform us well enough. They give clinical explanations. What we know we taught ourselves and Googled… It is difficult to inform yourself. It is disappointing that only one doctor recommended surgery. If I knew earlier, I would take her much earlier and not exposed her to so much medication and for the difference it could have on her personality (mother of Family 8).

Compliance with and the use of the right medication made a positive difference to almost all the patients and families. The right treatment and medication improved many of the patients' academic performance. Most of the patients were currently seizure-free and their anti-epileptic medication controlled their seizures well.

For me it is just fantastic that she (patient) is stable, and it is a low dosage. That pinpoints to me the severity and the grade of the epilepsy (mother of Family 6).

To be compliant with the taking of the medication can be stressful and intense. She (patient) has to carry her medication with her and cannot take it without eating something (mother of Family 8).

I only stared and looked around to see where I am. I am seizure-free since I use the medication (patient of Family 15).

Many patients received hospital treatment for their epilepsy. Good family support seemed to be present in only one family. Positive change took place during the interviews with half of the families as it seemed that to talk about the epilepsy brought relief to the families and brought better insight to the families in their experience of epilepsy and regarding their own behaviour towards epilepsy. The researcher perceived that it helped to facilitate sessions where the patient and family could talk about epilepsy. The researcher recommended psychotherapy directly to almost a third of the families.

I do not want to be the educational father any more. I want to be the supportive father (stepfather of Family 5, as part of his own summary of the interview).

Some discovered that speaking about stress in their lives helped; while some spoke to meaningful others, others consulted professionals.

It helps me to be able to talk about other stressful experiences in life... I consult with a psychiatrist (patient of Family 6).

For me, to cope with the epilepsy, it is important that I also receive support (mother of Family 6).

I believe in support. My coping skill is to talk to other people (mother of Family 10).

- ***Meaningful others.***

The support from meaningful others was imperative for the participating families' overall functioning. Many families felt that it was important that their friends knew about the diagnosis of the patient in order to cope better with the situation and enable their friends to support them. It seemed as though support from meaningful others for the patient and family members was important for the overall coping, wellbeing and functioning of the family.

Our friends know that our son has epilepsy (mother of Family 13).

If we got hold of the family earlier, it would be easier to cope and that, for example, my aunt could be there to support us (patient of Family 6).

He (brother) is a pillar of strength (mother of Family 7).

It is important to support one another (mother of Family 8).

I talk to a friend who understands and looks out for me and forms part of my support (mother of Family 3).

I miss my mother a lot. She was a big support to me (mother of Family 11).

Most of the patients could not recall what happened during seizures and therefore, someone had to help take responsibility for the patient. The responsibility fell mostly on some of the family members. It is important to support and empower meaningful others so that they can better support patients and their families.

I cannot support him (patient) but I can support her (mother). I am rather the supportive element and help her (mother) so that she can handle the situation (stepfather of Family 5).

I was so focused on her health that no one else mattered. I was in tunnel vision (mother of Family 6).

We help one another when there are difficult things (father of Family 9).

Meaningful others tended to lack insight and knowledge about epilepsy.

I do not think that it will have an emotional and physical impact on me… I was very chilled out through all of this. I was very calm… I am very sure that it affects you (mother) more than me. I am very mellowabout this (patient of Family 6).

The neurologist told us then for the first time that it is not witchcraft (father of Family 2).

There also seemed to be a lack of good communication. Many of the patients, well as the family members, do not seem to talk a lot about the diagnosis to each other or other meaningful others in their lives. Especially the fathers seem to not talk about aspects related to epilepsy.

He does not talk to anybody about this (epilepsy). He (father) internalises and is not a great talker (mother of Family 6).

He (father) suffers because he does not talk about this…he talks a little to me and then keeps quiet (mother of Family 10).

We do not discuss it (epilepsy) as a topic (between father and mother) (mother of Family 3).

It is a taboo to talk about the epilepsy (mother of Family 13).

Friends that provided support fulfilled an important role and made a positive difference in the families' experience of the diagnosis.

If she (patient) gets ill and I cannot attend to her, my friend will be able to fetch her (mother of Family 10). *My friends do not act different to me because of epilepsy* (patient of Family 15).

I talk to a friend who understands and looks out for me and forms part of my support (mother of Family 3).

- ***Parents' place of employment.***

There was a lack of support from the parents' place of employment and little understanding of what epilepsy entailed.

Her father's work is not supportive. They do not understand and is not willing to bend. Should the patient need admittance in hospital, his employer would not give him time off… My work does not support me anymore. They got fed-up. Then it happened that I started to talk less about it at work. If I get asked I will tell, but if I don't get asked, I don't talk (mother of Family 3).

Some parents experienced better support and understanding from their employers.

They (people at father's work) are never funny about it (that he sometimes takes time off from work to support the patient with medical visits), (father of Family 9).

My phone is allowed to ring... I work in an open plan office and when the phone rings and says 'school' everyone knows (what it means) (mother of Family 9).

5.2.3.10 Summary of main themes from the interviews.

The following themes relating to family processes and functioning emerged from the interviews: Families and patients' challenges besides epilepsy; family structure changes; distal and proximal hope and communication; concerns about the health and future of the patients; the primary caregivers' responsibility and burdens; coping with the diagnosis; the positive influence of knowledge about epilepsy; the emotional experience of patients and family members; the positive impact of support; and the role of the larger systems.

In this section, the themes, subthemes, and codes derived from all the interviews were described. The themes derived from the Graphic Family Sculptings of patients and their family members are explained next.

5.2.4 Graphic Family Sculpting (GFS) as Part of Qualitative Data Collection

Three of the GFSs, as drawn by the participants, including their analyses forms part of Appendices V1-V3 and serve as examples of the technique.

Overall, there were 12 and 14 drawings done by the patients and family members, respectively. Three families only had one child. In one family, the mother was divorced and the father not present and they did not draw anything. For consistency, the researcher interpreted the drawings of the patients and primary caregivers if they participated during the administration of the GFS.

Information that the participants did not share during the interviews became available through the GFS. The patient of Family 6, for example, clearly indicated in her GFS that she did not have a good relationship with her mother and that she experienced her mother as problematic; however, she made no direct comment about this during the interview.

The GFS included detail. Furthermore, the participants' responses to the stimulus questions asked by the researcher about the drawings were rich in meaning and provided valuable information, which enhanced the themes. All the patients drew detailed and rich drawings. Sometimes, their drawings were even richer than those of the primary caregivers. There was, however, one sloppy and coarse drawing (Family 11); furthermore, the writing on the drawing was difficult to read. Everyone, with the exception of one of the mothers, was able to indicate all the people's horizontal positions, viewing directions, labels and emotions. The co-coder and developer of GFS noted that 30 years of experience using this technique has demonstrated that it is common for some people to apply question marks to some of the dimensions mentioned above (Venter, personal communication, 2015, 2016, 2017, 2018). All the people, excluding the mother of Family 1, could follow the instructions. However, two of the patients drew the family members as stick figures.

The answers that the participants had to write on the back of the sheet of paper after each instruction provided valuable data that supported and highlighted the assumptions made through the drawings. Although the drawings by the patients sometimes differed from those of their father or mother, the similarities were sometimes also remarkable. The latter may suggest they experienced family interactions similarly or it may indicate more suffuse boundaries. Although the emotions and labels were sometimes different, in many of the cases, these were only nuanced differences about the same aspect. This may indicate the family members' similar emotional experiences and roles.

On some of the dimensions, some of the drawings of the families corresponded with each other. This may indicate that families in similar situations might have similar experiences. The co-coder indicated that this was not unique or unusual. For example, most of the people were drawn on one horizontal line and not on different levels, in a circle, in a circle with one person (normally the identified patient) in the middle, or in circles that overlapped to some extent.

A few aspects in some of the drawings were unique. It was only the second time in the co-coder's experience with the technique that such uniqueness, something drawn previously, came to the foreground. For example, one circle inside another circle, and circles tilting downwards to the right indicate hierarchy. Another unique phenomenon is that one of the fathers drew faces inside the circles; something that rarely occurs. In one drawing, the circles had a strange shape. Something observed for the first time in the researcher and co-coder's experience with this technique was that two of the mothers indicated the labels for the people were animals. For example, one mother represented all of the labels as elephants with the exception of one person who was labelled a giraffe. In one drawing, the question mark (?) depicted one of the people as an animal. Another unique aspect was that one patient (Family 2) drew the circles from right to left. It is recommended that the unique nature of the examples noted above be explored in further research on epilepsy and GFS as an examination of the unique nature of the participants' drawings did not fall within the scope of this study.

The coding and co-coding for each family's GFS can be found in Appendices V1-V3.

5.2.5 Description of GFS of 15 Families as a Group

In three of the GFSs (Families 3, 8, and 13), only one parent drew. Furthermore, in one GFS (Family 15), only the patient made a drawing. With one GFS (Family 14), only the patient and two siblings drew; furthermore, the middle sister of the patient acted as the primary caregiver in the study. The rest included the patient and one or more family members, including the primary caretaker. Detail of the different dimensions of GFS follows. First, a summary of the important features found in the patients and primary caregivers' drawings is provided. This is followed by a summary and interpretation of the themes of each dimension.

5.2.5.1 Order, size, and shapes of circles.

- ***Drawings by patients.***

Of the 15 patients, 12 drew a picture. Eight patients drew the father and mother next to each other (Families 2, 3, 4, 6, 9, 12, 14, and 15). The father was absent in one drawing because of a divorce. The patient was placed in the middle between the parents in three of the drawings. In Family 1, the patient and his two sisters were drawn between their parents. In Families 1 and 2, the patient drew the family members as stick people. Because this is unusual, the researcher considered whether it was possibly a comment on delayed emotional and/or cognitive development. The other information in these drawing was rich though and could be used as part of thematic formulation. In five drawings, the patients drew themselves smaller than the rest of their families. Furthermore, in Families 1 and 2, the patients drew one or two of the other family members markedly smaller than the rest. In Family 12, the mother was drawn smaller than the rest of the family. This might indicate that the patient did not perceive their roles to be important. Furthermore, the circles, drawn from big to small in two drawings, in Families 7 and 9, may possibly have indicated the relative importance of their roles to these patients.

- ***Drawings by primary caregivers – mostly mothers, one father, middle sister.***

The primary caregivers of 14 families made drawings. The primary caregiver of Family 13 did not draw a picture. In Family 14, two siblings drew pictures; there was no parent and thus, the middle sister's drawing was used. The father and mother were drawn next to each other in 14 of the drawings. The researcher wondered if the patients' representation of the situation was more accurate. In one of the drawings, the father was absent because of divorce. In Family 1, the mother's circles had strange shapes; this may have indicated delayed emotional or cognitive functioning. The mothers of Families 5 and 11 drew themselves markedly smaller; it is possible they experienced their roles as being less significant in the family. In Family 5, the mother drew herself inside the father, possibly indicating that she found her own identity in her husband. The mother of Family 7 drew her eldest son slightly bigger than the rest of the family, perhaps experiencing his role as more prominent than the rest of the family; she was divorced from her husband and he did not feature in the drawing. The mothers of Families 9 and 10 drew the fathers slightly bigger than the rest of the family, possibly indicating his role was more prominent. In Family 10, the mother was drawn slightly bigger than the children; possibly an indication of her role being more prominent. The patients and primary caregivers of Families 1, 2 and 3 added other family members besides the nuclear family members.

- ***Summary of themes.***

Eight patients drew their father and mother next to each other in comparison with all the primary caretakers that drew them next to each other. This may indicate that the primary caretakers experienced the marital relationships to be better or wanted it to be better than the patients' perception thereof. In three of the drawings, the patients placed themselves in the middle of their parents. This may be indicative of distance between the parents and possibly, the patient played a significant role in the management of their relationship (triangulation). The patients drew themselves smaller than the rest of the family in five drawings; they possibly experienced low self-esteem or believed they were the least significant in the family. In three drawings, the patient and primary caregiver added other family members outside the nuclear family, possibly suggesting they played a significant role in their families. Whereas the primary caregivers experienced the marital relationship as good, most of the patients did not perceive this. Some of the families experienced triangulation in their relationships with the patient being part of the triangle between mother and father.

5.2.5.2 Gestalt and position of each person in gestalt and hierarchy levels.

To some extent, the primary caregivers and patients' position in the gestalt has already been discussed.

- ***Drawings by patients.***

Ten patients drew all the people on the same horizontal level (Families 1, 2, 4, 5, 6, 7, 9, 11, 12, and 15). In Families 10 and 14, the family members were drawn on two horizontal levels. This demonstrated that most of the patients experienced all the family members on the same hierarchical level and two perceived certain members of their families to be on a higher hierarchical level.

- ***Drawings by primary caregiver.***

In Families 4, 5, 7, 11, and 12, the people were drawn on the same horizontal level. Some primary caregivers drew one or more people on a lower level. In four families, they were drawn on two horizontal levels (Families 1, 2, 3, and 14) whereas three horizontal levels were used in three families (Families 6, 10, and 13). In Families 8, 9 and 14, there was a gradual 'dip' in circles in a downward direction. This may have been indicative of hierarchy, where certain members of their families were perceived to be on lower or higher hierarchical levels than other members.

- ***Summary of themes.***

Ten patients drew all the people on the same horizontal level in comparison with five drawings of family members. The primary caregivers drew the family members on two and three horizontal levels. The family members' drawings were possibly more indicative of hierarchy levels in the families than the drawings of the patients. Furthermore, more family members experienced a difference in the hierarchy levels of the family members. More family members placed parents on a higher hierarchical level than they did the patients and their siblings. Higher hierarchical levels may indicate higher levels of prominence, authority or having a more significant role in the family while lower hierarchical levels may suggest less authoritative or significant roles in the families. The family members appeared to be more aware than the patients of hierarchy levels within the family. The parents and primary caregivers were placed on a higher hierarchical, authoritarian or significance level than the patients and their siblings.

5.2.5.3 Horizontal behaviour / Standing, sitting, lying down.

- ***Drawings by patients.***

Of the 12 drawings by patients, the family members of only Family 1 stood. The patient stood in five of the drawings (Families 1, 9, 10, 12, and 14). The patient sat in three drawings (Families 4, 6, and 15). In four of the drawings, namely, Families 2, 5, 7 and 11, the patient was lying down. In Families 9 and 10, the mother was lying down. The father was not lying down in any of the drawings.

- ***Drawings by primary caregivers.***

In the primary caregivers' drawings, the family members were standing in only one of the 14 drawings, namely, that of Family 5. The patient stood in four of the drawings (Families 5, 7, 12, and 13) and sat or lay down in four of the drawings (Families 4, 8, 10, and 14). In Families 1 and 2, the patient was lying down and sleeping, in Families 3 and 6, the patient was lying down comfortably, and in Families 9 and 11, the patient was lying down and resting. The mother was lying down in only two of the drawings (Families 1 and 10) while the father was lying down in four of the drawings (Families 3, 4, 10 sits-lies down, and 13).

There were significant differences between the indications of the patients and primary caregivers. It is of concern that the patients were lying down as this could indicate passivity or weakness (Families 2, 5, 7, and 11).

- ***Summary of themes.***

Lying down behaviour is indicative of a more passive role while standing denotes a more active role. While only one (Family 1) of the 12 drawings of the patients and one (Family 5) in the 14 primary caregivers' drawings drew people standing, one can assume that only one family played an active role. The patient stood in five drawings (Families 1, 9, 10, 12, and 14), sat in three drawings (Families 4, 6, and 15), and lay down in four of the patients' drawings (Families 2, 5, 7, and 11), respectively. Furthermore, the patients stood in four drawings (Famlies 5, 7, 12, and 13), sat in four drawings (Famlies 4, 8, 10, and 14) and lay down in six drawings (Families 1, 2, 3, 6, 9, and 11) of primary caregivers' drawings, respectively. As noted previously, it is of concern that the patients were drawn lying down because it may be indicative of passivity or weakness. The mother was lying down in two of the patients (Families 9 and 10) and caregivers' (Families 1 and 10) drawings. While the father was not lying down in any of the patients' drawings, he was lying down in four (Families 3, 4, 10, and 13) of the primary caretakers' drawings. This may be a sign of passivity. There were significant differences between the patients and primary caregivers' indications, suggesting that they experienced the passivity or activity in the families differently. The families were perceived as being more passive in their actions and reactions. Furthermore, the patients' passivity is of concern.

5.2.5.4 Looking behaviour.

- ***Drawings by patients.***

Looking behaviour may be an indication of persons being involved with one another. It can also indicative of admiration or looking up to, taking care of and spending time with another. The father and mother only looked at each other in four of the patients' drawings (Families 9, 10, 12, and 14). While the mother looked at the father in three of the drawings (Families 2, 7, and 14), the father only looked specifically at the mother in Family 14. In five of the drawings, the father looked to the front, away or up (Families 1, 2, 5, 11, and 15). However, the mother only looked away in Family 11. The mother looked primarily or secondarily at the patient in five of the drawings. The father looked primarily or secondarily at the patient in three of the drawings. In six of the drawings, the patients looked at one of their siblings while some of the siblings looked at the patient.

- ***Drawings by primary caretakers.***

The father and mother looked at each other in only two of the drawings (Families 4 and 12). However, the mother looked at the father in Families, 2, 5, 7, and 8. While the father looked at the mother in four of the drawings, he looked (away, to the front or up in seven of the drawings. The mother only looked away in Family 1. In eight of the drawings, the mother looked primarily or secondarily at the patient (Families 3, 5, 6, 7, 8, 10, 13, and 14). The father looked at the patient in two of the drawings. Two of the primary caregivers drew the patient looking at a sibling or a sibling looking at the patient. In four of the families, the mother appeared to be more involved with her husband (Families 2, 5, 7, and 8) and in eight of the families with the patient (Families 3, 5, 6, 7, 8, 10, 13, and 14) than the father was with the mother (Families 3, 13 and 14) or the patient (Families 2 and 6).

- ***Summary of themes.***

The mothers were more involved with their husbands and the patients than the father was with the mothers and patients. The mothers as primary caregivers were more involved with the family members, especially the fathers and patients than the father was.

5.2.5.5 Marital subsystem.

- ***Drawings by patients.***

Six of the twelve patients indicated that the marital sub-system was possibly intact and functioning well (Families 4, 5, 9, 10, 12, and 14) while five of the patients indicated that the marital subsystem possibly had problems (Families 1, 2, 6, 11, and 15).

- ***Drawings by primary caretakers.***

Three of the primary caregivers indicated that the marital subsystem was intact (Families 4, 5, and 9) while nine of the primary caregivers indicated that the marital sub-system had problems (Families 1, 2, 3, 6, 8, 10, 11, 13, and 14). It appeared as though the marital subsystem of most of the families did not function very well. The parents, in particular, were negative regarding the functioning of the marital subsystem.

5.2.5.6 Sibling subsystem.

- ***Drawings by patients.***

Three families only had one child and thus, did not have a sibling subsystem (Families 5, 6, and 11). Only three of the nine patients with siblings indicated that the sibling subsystem was possibly intact (Families 1, 2, and 9). Six of the nine patients with siblings indicated that the sibling subsystem was possibly not intact or did not function well (Families 4, 7, 10, 12, 14, and 15).

- ***Drawings by primary caretakers.***

The primary caregiver in Family 15 did not participate. Furthermore, in Family 14, a sibling participated instead of a parent. Only two of the primary caregivers of the 12 families with siblings indicated that the sibling subsystem was possibly intact (Families 1 and 9) while nine of the primary caregivers indicated that the sibling subsystem was possibly not intact

(Families 2, 3, 4, 7, 8, 10, 12, 13, and 14).

- ***Summary of themese.***

In essence, the sibling subsystem was not positive as six of the nine patients with siblings indicated that the sibling subsystem possibly did not function well (Families 4, 7, 10, 12, 14, and 15). Nine of the primary care takers indicated that the sibling subsystem was possibly not intact (Families 2, 3, 4, 7, 8, 10, 12, 13, and 14). Two of the three basic subsystems, namely, the marital and sibling subsystems, did not appear to function well in most of the families; there did not appear to be enough emotional support or involvement in one another's lives.

5.2.5.7 Labels.

The patients appeared to experience the fathers as more positive than their mothers. More primary caregivers allocated negative labels to the mother than to the father. It is possible that the mothers were more involved with the patients and their care and consequently, the patients viewed them as more negative. It is also possible that the mothers felt overburdened because of the extra input in the household. It was easier for the patient to classify a label as positive or negative as there were less neutral labels allocated than with the primary caretakers. The families experienced the mothers to be more negative and perhaps overburdened.

5.2.5.8 Emotions.

Both groups allocated negative emotions to the mothers. The emotion allocation by the patients correlates well with their label allocation. The mothers often had a negative allocation. A large group of patients allocated negative emotions to themselves as patients and received negative emotion allocations by their parents; in almost 50% of both groups. This concurs with the label allocation. The families perceived the mothers to be more negative and the mothers experienced this too.

5.2.5.9 Additional questions.

Most of the patients did not become emotional during the GFS while most of the primary caregivers did. More caregivers indicated that they learned something during the administration of the GFS than the patients did. The parents found it easier to draw. This 'learning' of new information during the GFS has implications for testing. It may be better for diagnostic evaluation to first do paper-and-pencil tests and then the GFS. If the GFS is administered first, there is a possibility that it may contaminate the other test results if the other tests have the same objectives and are measured in the same way.

5.2.6 Summary of GFS Themes

The themes derived from the GFS are summarized in Table 5.10.

Table 5.10

Summary of Results from GFS

Theme	Drawings by P	Drawings by FM	Meaning of themes
Order, size, and shapes of circles	- 8 P drew F and M next to each other - In 1 drawing F is absent - divorce - P drew self in the middle between the parents in 3 drawings - P drew him/herself smaller than the rest of the family in 5 drawings - P added other FM in the drawing in 3 drawings	- All PCG drew F and M next to each other - PCG added other FM in the drawing in 3 drawings	- PCG experienced the marital relationship to be better, or want it to be better, than what the P experience it to be - Some P experienced distance between the parents - Some P might experience a low self-esteem or a less significant role in their families - Some families have other FM other than their nuclear family that fulfill a significant role in their families
Gestalt and position of each person in gestalt and hierarchy levels	- 10 Ps drew all people on the same horizontal level	- 5 PCG drew all people onthe same horizontal level - FM are on 2 horizontal levels with some PCG - FM are on 3 horizontal levels in 3 drawings of PCG	- Drawings of PCG indicated more about the hierarchy levels in the families than the drawings of the P. More FM experienced differences in the hierarchy levels of the FM - more PCG placed parents on a higher hierarchical level than the P and siblings indicating a more prominent or less significant role
Horizontal behaviour / standing, sitting, lying down	- FM all stand in only 1 out of 12 drawings made by P - P stands in 5, sits in 3 and lies down in 4 drawings made by P - M lies down in 2 drawings made by P - F does not lie down in any of the drawings made by P	- All FM stand in only 1 of the 14 drawings made by PCG - The P stands in 4, sits in 4, lies down in 6 of the drawings made by PCG - M lies down in 2 drawings made PCG - F does not lie down in 4 drawings made by PCG	- Large differences between indications of Pand PCG - experience passivity or activity in the families differently. Lying down behaviour indicates a more passive role and standing indicates a more active role - Lying-down behaviour of patients is of concern - can indicate passivity, weakness
Looking behaviour			- It looks as if M is more involved with her husband and P than what F is involved with M or P, with M taking a more prominent or significant role
MS	- 6 of 12 P indicated that the MS is possibly intact and functioning well - 5 P indicated that the MS possibly has problems	- 3 of the PCG indicated that the MS is intact - 9 PCG indicated that the MS has problems	- It seems that the MS for most families did not function too well, indicating strain in the marital relationship - The parents especially indicated negative outlooks, perhaps an indication of a depressive mood, or a larger realization of the difficulty of their situation, or perhaps feeling overburdened
S	- 6 out of 9 P with siblings indicated that the SS possibly does not function well	- 9 of the PCG indicated that the SS is possibly not intact	- Overall view of the SS does not seem to be positive, and indicates strain in the relationships with and among siblings - 2 of 3 basic subsystems - MS and SS - do not seem to the researcher to function well - not enough emotional support or involvement in each other's lives indicated by the P and PCG
Labels	- It seems that P experienced the F to be more positive than the M - It was easier for P to classify a label as positive or negative as there are less neutral labels allocated than to the PCG	- More PCG allocated negative labels to M than to F	- It could be that the M are more involved with P and their care and P view them as more negative, indicating a depressive mood or feeling overburdened - It is possible that M feel overburdened because of extra input in the household
Emotions	- Many M have negativeemotions allocated by P - Emotions allocated by P correlates well with their label allocation - A big group of P allocated negative emotions to themselves and received negative emotion allocations by PCG- – almost 50% of both groups, correlates with label allocation	- Many M have negative emotions allocated by PCG - Emotion allocation of PCG to M is more negative than the label allocation	- M often had a negative allocation, perhaps because of a depressive mood, or feeling overburdened, or being the one taking the most responsibility
Additional questions	- Most P did not get emotional during GFS	- Most PCG got emotional during GFS - More PCG indicated that they learned something during the application of GFS than the P did - PCG found it easier to draw	- Perhaps because of their better insight in their situation, feeling the effect. - PCG perhaps had better insight in the GFS and could relate to their experience - The 'learning' of new information during GFS has implications for testing - can be good, for diagnostic evaluation, to first do paper-and- pencil tests and then GFS

* P = patient; PCG = primary caregiver; M = mother; F = father; FM = family member; MS = marital sub-system; SS = sibling sub-system

5.2.7 Summary of Qualitative Results

Under the two overarching themes of family processes and family functioning, ten themes emerged from the semi-structured interviews to describe patients' and family members' experiences and seven themes emerged from the GFS. This is summarized in Table 5.11.

Table 5.11

Summary of Emerging Themes from the Interviews and GFS

Themes from interviews	Themes from GFS
- Participants face other challenges as well - The family structure changed after diagnosis - Distal and proximal hope and communication as part of processes - Concerns about the health and future of the patient - Role of the primary caregiver as having much responsibility and being overburdened - Patients and family members do different things to try to cope with the diagnosis - Knowledge about epilepsy makes a positive difference in functioning and coping of patients and family members - To receive the diagnosis and live withit is an emotional experience - for patients and family members - Support makes a positive difference in family functioning and coping strategies Role of larger systems makes a difference in the functioning and coping strategies of families	- Drawings of family members indicate more about hierarchy levels in families than drawings of the patients do - Mothers seem to be more involved with their husbands and the patients than what the fathers are involved with the mothers or patients - Overall view of the sibling subsystem is not positive according to patients and primary caregivers - Many mothers have negative emotions allocated by patients and primary caregivers - A big group of patients allocated negative emotions to themselves as patients and received negative emotion allocations by primary - Caregivers - Most patients did not get emotional during the GFS while most primary caregivers did - More caregivers learned something during the application of the GFS than patients did - Primary caregivers found it easier to represent the family sculptings than the patients did

The family experiences and impact of epilepsy on family processes according to the patients and family members is presented In Table 5.12.

Table 5.12

Experiences and Comparison of Patients and Family Members' Experiences

Experiences of patients	Experiences of family members
- patients and family members do different things to try to cope with the diagnosis - knowledge about epilepsy makes a positive difference in functioning and coping of patients and family members - to receive the diagnosis and live with it is an emotional experience for patients and family members (especially primary caregivers) - many primary caregivers and patients experience negative emotions - support by meaningful others, including larger systems, e.g., the school, makes a positive difference in family functioning and coping strategies - overall view of the marital and sibling sub-systems is not positive according to patients and primary care takers – marital strain, sibling rivalry and different treatment of children are present	- family members express more concerns about the health and future of the patient than the patients - primary caregivers seem to take more responsibility for the support regarding the diagnosis, more realise the impact of the diagnosis and end up feeling overburdened – more than the patients do - more mothers seem to take up the role of primary caregiver than fathers do - patients and family members do different things to try to cope with the diagnosis - knowledge about epilepsy makes a positive difference in functioning and coping of patients and family members - to receive the diagnosis and live with it is an emotional experience for patients and family members (especially to primary caregivers) - many primary caregivers and patients experience negative emotions - support by meaningful others, including larger systems e.g. the school, makes a positive difference in family functioning and coping strategies - overall view of the marital and sibling subsystems is not positive according to patients and primary caregiver - marital strain, sibling rivalry and different treatment of children are present - more primary caregivers earned something during the application of the GFS than patients did and found it easier to represent the family sculptings than the patients did – perhaps better insight in bigger impact of epilepsy?

In Tables 5.13 and 5.14, the integrated quantitative and qualitative findings are outlined.

Table 5.13

Integration of Quantitative and Qualitative Results Between Patient and Family Groups

Type of findings	**Patients**	**Family members**
Quantitative findings	- Family and patients do not significantly differ in the reporting of family satisfaction, functioning, hardiness, and general functioning. - There is moderate evidence of significant difference in worse experience of family functioning. - There is moderate evidence of significant difference on lower family identity. - There is moderate evidence of difference on affective responsiveness and behavioural control.	- Family and patients do not significantly differ in the reporting of family satisfaction, functioning, hardiness, and general functioning. - There is moderate significant evidence of better of difference on experience of family functioning. - There is moderate significant evidence of difference on higher family identity. - There is moderate evidence of difference on affective responsiveness and behavioural control.
Qualitative findings	- Patients face other challenges as well. - The family structure changed after diagnosis and patients experienced the hierarchy levels in the family to be different. - Distal and proximal hope and communication form part of the process. - Patients appear mostly unaware of the impact of the diagnosis. - Patients do a variety of things to try to cope with the diagnosis. - Knowledge about epilepsy makes a positive difference in functioning and coping of patients. - To receive the diagnosis and live with it is an emotional experience for patients - many patients experience negative emotions. - Support by meaningful others, including larger systems, makes a positive difference in family functioning and coping strategies for patients. - Overall view of the marital and sibling subsystems is not positive according to patients – marital strain, sibling rivalry and different treatment of children are present. - Fewer learned something during the application of the GFS. - Found it more difficult to represent the family sculptings. - Took less responsibility regarding the diagnosis.	- Family members face other challenges as well. - The family structure changed after diagnosis and family members experience the hierarchy levels in the family to be different. - Distal and proximal hope and communication form part of the processes. - There are concerns about the health and future of the patient. - Family members do different things to try to cope with the diagnosis. - Knowledge about epilepsy makes a positive difference in functioning and coping of family members. - To receive the diagnosis and live with it is an emotional experience for family members (especially primary caretakers) - many primary caretakers experience negative emotions. - Support by meaningful others, including larger systems, makes a positive difference in family functioning and coping strategies for family members. - Overall view of the marital and sibling subsystems is not positive according to family members – marital strain, sibling rivalry and different treatment of children are present. - More family members learned something during the application of the GFS. - Found it easier to represent the family sculptings - Possibly better insight into bigger impact of epilepsy(?) - Role of the primary caregiver as taking more responsibility regarding the diagnosis and being overburdened - mothers seem to be more involved with their husbands and the patients than what the fathers are involved with the mothers or patients.

Table 5.14

Integration of Differences and Similarities Between Quantitative and Qualitative Results

Differences/ similarities	Quantitative results	Qualitative results
Differences	- Indication of difference between younger and older patients regarding adaptability, satisfaction and problem- solving. - Indication of a difference in the coping of patients in a lower income group. - Indication of a difference in cohesion and the type of epilepsy. - Moderate indication in significance that families experience family functioning and family identity to be better. - No indication that family members report being more affected by the diagnosis. - Does not explain changes in family structure and interaction. - Does not elaborate on distal and proximal hope and communication and on concerns regarding the patient's health and future. - Does not express the role of the primary caregiver and the overburdening part of this role. - Does not indicate that knowledge regarding epilepsy and support for epilepsy makes a meaningful positive difference in functioning and coping. - Could not explore different strategies that families apply in order to try to cope with the diagnosis.	- No indications of a difference between younger and older patients regarding adaptability, satisfaction and problem- solving. - No indication of a difference in the coping of patients in a lower income group. - No indication of a difference in cohesion and the type of epilepsy. It seems to the researcher that affection on emotional level is similar in families with patients with different types of epilepsy. - No indication that families experience family functioning and family identity to be better. - Family members report being more affected by the diagnosis. - Explain changes in family structure and interaction better. - Elaborate more on distal and proximal hope and communication and on concerns regarding the patient's health and future. - Express the role of the primary caretaker and the overburdening part of this role. - Indication that knowledge regarding epilepsy and support for epilepsy makes a meaningful positive difference in functioning and coping. - Could explore different strategies that families apply in order to try to cope with the diagnosis. - Indicate the depth of the emotional experience that comes with the diagnosis.
	- Does not indicate the depth of the emotional experience that comes with the diagnosis. - - Could not pick up the depth of strain on marital and sibling subsystems.	- - Could better pick up the depth of strain on marital and sibling subsystems.
Similarities	- Patients and family members face other challenges as well. - - Findings indicate that the diagnosis of epilepsy affects the functioning and coping of patients and family members.	- Patients and family members face other challenges as well. - - Findings indicate that the diagnosis of epilepsy affects the functioning and coping of patients and family members.

The integration is interpreted and discussed in Chapter 6.

5.3 Conclusion

The results outlined in this chapter are organized around the quantitative and qualitative research aims of this study. The researcher compared differences between the patients' and family members' family process profiles. A brief description of each family, a summary of the characteristics of the group, and thematic analyses of the interviews and the GFS, with the focus on themes identified from the group as a whole based on the qualitative aims of this study are outlined. Analysis, conclusions, and recommendations in relation to the interpretation of results are discussed in Chapter 6.

CHAPTER 6: DISCUSSION

In this chapter, as the conclusion to the research study, the major findings are highlighted, the value of the study evaluated, and the advantages and strengths thereof are described. Furthermore, the limitations of the research, recommendations in relation to the implications for practice and further research, and conclusions are discussed.

6.1 Quantitative Findings: The Family Process Profiles as Reported by Patients and Family Members

Research questions: First, what are the family process profiles, namely, family satisfaction, family functioning, and hardiness reported by the patients and their family members? Second, what are the differences and similarities within patients and between the patients and their family members' family process profiles, namely, family satisfaction, family functioning, and hardiness?

On the family process profiles, the mean was higher for the family members than the patients on the levels of family satisfaction, family functioning and hardiness, thus, indicating better outcomes. In relation to family satisfaction, the family members felt more satisfied with respect to their levels of cohesion, which comprised emotional bonding, family boundaries, coalitions, time, space, friends, decision-making, interests and recreation than the patients felt about this. Furthermore, the family members also felt more satisfied about their levels of adaptability. According to Olson and Wilson (1982), the latter consists of assertiveness, control, discipline, negotiation, roles and rules. In relation to family functioning, as initially postulated by Trivette et al. (1990), more family members than patients in this study believed that their families were characterized by different strengths and capabilities. In addition, with respect to family hardiness, as initially proposed by Trivette et al. (1990), more family members than patients in this study experienced their families as having internal strengths that control life events and hardships, and produce positive changes and growth in the family unit.

On general functioning, as measured on the FAD (Stevenson-Hinde & Akister, 1995), the patients reported better outcomes than their family members. Therefore, the patients perceived themselves to function better overall in relation to overall health than how they perceived their family members to function. This corroborates to some extend with the research done by Mu (2008) that revealed that parents tend to suffer in silence. It also contradicts the research findings by Gazibara et al. (2014) that revealed that parents want their family and friends to know that their child has epilepsy. Stuart and Jose (2012) also found significant discrepancies between adolescents' and parents' perceptions of family functioning. Furthermore, in relation to their families, the patients experienced a higher level of the following concepts than their families experienced: the ability to solve problems at a level that maintains effective family functioning; communicating effectively in a clear, direct way; assigning roles and establishing patterns of behaviour to handle their family needs; exhibiting affective responsiveness and expressing appropriate affect over a range of situations; demonstrating affective involvement by appreciating each other's activities and concerns; and displaying behaviour control in maintaining standards of behaviour. It is possible that the patients experienced their own overall functioning as better than the family members.

The family members, especially the primary caregiver, tended to experience the impact of the epilepsy more and took more responsibility for the management thereof. This corroborates with research done by Dehn et al. (2014), Spangenberg and Lalkhen (2006) and Ryu et al. (2015). It is possible that patients experience more congruent communication and better resilience than their family members and this corroborates research done by Becvar (2007), Becvar and Becvar (2014) and Masten and Reed (2005).

Family process profiles encompass the integration of family satisfaction, family functioning, family hardiness and general functioning. While eight families perceived their family process profiles to be better than what the patients experienced them to be, three patients perceived their family process profiles to be better than their family's experience thereof.

When examining the results to the FAD in accordance with the McMaster model of family functioning (Epstein et al., 1983; Epstein et al., 2003), eight families experienced healthy functioning with healthy levels of problem-solving, communication, correct allocation of roles, demonstration of affective responsiveness, affective involvement and flexible behaviour control. It appeared as though the family members experienced the general functioning of the families to be better than the patients did. Furthermore, results from this research revealed that younger patients appear to solve problems in a more effective manner than older patients do. Accordingly, this supports the healthy functioning and stability of the younger patients who are not very vulnerable to unresolved problems. This does not corroborate or contradict specific findings in the literature review.

According to the Circumplex model of marital and family systems, family cohesion and flexibility or adaptability are important for the effective functioning of families (Becvar

& Becvar, 2017; Olson, 2002). Almost half of the families in this study experienced their levels of cohesion and adaptability as satisfactory, were more balanced and generally functioned adequately. These families experienced satisfactory levels of cohesion within the family in relation to emotional bonding, family boundaries, coalitions, time, space, friends, decision- making, interests and recreation. Furthermore, they experienced satisfactory levels of adaptability in relation to assertiveness, control, discipline, negotiation, roles and rules. Two families were very dissatisfied and concerned about their families and dissatisfied about their levels of cohesion and adaptability, as noted previously. Under a quarter of the patients experienced satisfactory levels of cohesion and adaptability and enjoyed most aspects of their family. In addition, approximately a quarter of the patients were dissatisfied about their levels of cohesion and adaptability and extremely dissatisfied and concerned about their families. Half of the families and a quarter of the patients functioned adequately across the family cycle and although they could experience extremes, they discovered a balance; however, the other families and some of the patients were unable to find a balance. According to Olson (2010), families and patients high in family satisfaction enjoy significantly better family communication.

Twelve families, in comparison with five patients, experienced a high level of adaptive functioning, which characterizes families in accordance with their different strengths and capabilities. According to the Circumplex model (Olson, 2002; Olson et al., 1982), almost half of the families and just less than a quarter of the patients are more balanced and will perform better because they are able to change their family system in order to cope more effectively with illness in a family member. These families generally function more adequately across the family life cycle than unbalanced or extreme types. These families and patients are able to experience the extremes of cohesion when appropriate, but they do not typically function at these extremes for long periods and allow family members to experience being both independent from and connected to their family. Almost half of the families and just less than a quarter of patients were unbalanced. In relation to adaptability, these families and patients were able to maintain some level of stability in their system with openness to some change when necessary. These families had the skills and resources to shift their system so as to cope more effectively with a crisis (Olson, 2002; Olson et al., 1982).

6.1.1 Comparative analysis within the patient group

No significant differences were found between patient diagnostic profiles, illness duration, composition of families, and household income, which indicates that these aspects do not play a significant role within the patient group (refer to tables 5.4 and 5.5). For the

Coping 1 subscale of the FSS the p-value = 0.037 displayed a significant difference on the mean FFS score for male and female patients, indicating that the male patients were coping better. It is not indicated through the FFS subscale why the male patients were coping better. Only the difference was indicated.

Significant differences indicated by the Kruskal-Wallis test within the FSS found across the two age categories for the adaptability subscale of the FSS (p = 0.029) and on total family satisfaction (p = 0.045) (refer to Table 5.5), indicated that older patients (17 to 18 years) are coping better than the younger patients (14 to 16 years). This is interesting as the older patients did not necessarily have a longer duration of diagnosis. It can perhaps relate to the emotional maturity of younger patients therefore not coping as well as older patients or can perhaps relate to the challenges that go with the early adolescent years. Research done by Goldenberg and Goldenberg (2013) found that adolescents' age and level of development might influence their perception and understanding of trauma, exposure to risk, susceptibility to parental distress, coping styles, self-concept, adaptation and social skills, perhaps indicating that older patients might cope better.

6.1.2 Family Process Profiles: Differences and Similarities

A comparison of the process profiles of patients and family members (refer to Tables 5.2, 5.3, 5.5, 5.6 and 5.7) revealed certain differences: for the problem solving subscale of the FAD the p-value = 0.013 reflects a significant difference indicating that the patients experienced to have better problem solving skills than the family members. These findings are not corroborated or contradicted by other research in the literature review. Kerne and Chapieski (2015) identified other risk factors that might affect poor adaptive functioning: the use of more anti-epileptic medication, a longer duration of seizure disorder, seizures that generalize secondarily and a younger age at the onset of epilepsy.

The following similarities between the profiles of the patients and families were revealed. The family members and patients did not differ significantly in their reporting of overall family satisfaction (measured on FSS), overall family functioning (measured on FFS), overall family hardiness (measured on FHI) and overall general functioning (measured on FAD). Furthermore, more mothers appeared to take up the role of primary caregiver than the fathers did. In addition, knowledge about epilepsy made a difference in the patients' and family members' coping.

6.2 Qualitative Findings: The Experience of Families Living With an Adolescent Diagnosed With Epilepsy and the Impact on the Family Processes and Functioning According to the Patients and Family Members: Differences and Similarities

Research questions: *First, how do families experience living with an adolescent diagnosed with epilepsy? Second, what are the impacts of epilepsy on the family processes and functioning according to the patient and family members?*

Through the lens of systems theory, significant information about the families emerged. Furthermore, the researcher examined the whole family and not only the individual members of the family. This concurs with the view of general systems theory in that a system is a set of interdependent components, which form an internally organized whole that functions as one in relation to its environment and other systems (Poole, 2014). As noted by Becvar and Becvar (2017), the participating families had characteristics in common, which were separate from their internal elements. Change occurred because of the diagnosis of epilepsy. It was evident that a diagnosis of epilepsy initiated changes in the family functioning (refer to 3.7.2.1). According to family systems theory, each family organizes its system in a specific way and is characterized by specific behaviour. This behaviour serves a function in each family to try create equilibrium in their system (Fleming, 2003; Goldenberg & Goldenberg, 2013; Hanson, 2013). A diagnosis of epilepsy initiates changes in the family functioning and challenges the different roles of family members in the family all in an attempt to try to create equilibrium in their system. For example, in the study, one of the parents and at times, a sibling took on the role of the primary caregiver in an attempt to deal with the change and extra responsibility of managing the epilepsy.

According to family systems theory, the challenges involved with an adolescent diagnosed with epilepsy in a family affect all other members of the family and create conflict within their systems (Broderick, 1993; Fleming, 2003). Adolescents who suffer from epilepsy and their family are faced with life and death concerns when, according to Wood (1996), children should be most carefree. It appeared difficult for the family members to accept this. Although the subsystems must maintain boundaries to function well, it appeared as though the participating families tended to struggle with these boundaries because of marital and sibling subsystems, which were encountering strain. Circular or mutual causality is important in family systems. Moreover, it is evident that the reaction of a family member can influence the reactions of the other members (Bateson, 1979, 2000; Laszlo, 1996; Lederer & Jackson, 1968; Von Bertalanffy, 1981). This is in accordance with the researcher's view that families, especially primary caregivers, must receive support and knowledge about epilepsy from the onset of the diagnosis.

Patterns maintained by family members to support and improve the medical management and psychological functioning of the adolescent can have a negative impact on aspects of family functioning (Wood, 1996). For example, when the needs of a marriage or siblings were regarded as less important in order to provide intensive caregiving for the adolescent with epilepsy. If, however, the adolescent's diagnosis of epilepsy was not regarded as important, ongoing family functioning may be supported, but the medical and psychological health of the adolescent with epilepsy may be compromised (Wood, 1996). A comparison of the patients and family members' experiences (Table 5.13) revealed various differences and similarities.

Differences: Patients and family members employed different strategies to cope with the diagnosis. Family members expressed more concerns about the health and future of the patients than the patients did. This corroborates with the findings from a qualitative study conducted in Sri Lanka that found that parents with children with epilepsy were concerned about the education, safety, marital prospects, employment, unpredictability of seizures and unawareness of the influence of stigma associated with epilepsy (Murugupillai, Wanigasinghe, Muniyandi, & Arambepola, 2016). The primary caregivers appeared to take more responsibility for support in relation to the diagnosis and realized the impact of the diagnosis. Consequently, they felt overburdened; more so than the patients did. This corroborates with research done by Dehn et al. (2014), Spangenberg and Lalkhen (2006) and Ryu et al. (2015).Caring for adolescents with epilepsy is emotionally demanding; caregivers carry a burden and can suffer depression. This concurs with research conducted by Karakis et al. (2014).

Similarities: It appeared that knowledge about epilepsy made a difference in the patients and family members' functioning and coping. This corroborates to some extent the research by Jonsson et al. (2014) that suggested that early provision of information can increase knowledge about epilepsy and associated psychological co-morbidities.

Being diagnosed and living with epilepsy was an emotional experience for the patients and family members, especially primary caregivers. Furthermore, many of the primary caretakers and patients experienced negative emotions. Increased parental anxiety resulted in a lower quality of life for the patients. Furthermore, their parents often experienced symptoms of anxiety; this corroborates with research conducted by Jones and Reilly (2016). Support from meaningful others including larger systems such as schools made a positive difference to family functioning and coping strategies. Greater social support by family members, colleagues, friends and medical personnel resulted in a better quality of life for the patients; this concurs with Wang et al.'s (2015) findings.

The patients and primary caregivers did not perceive the marital and sibling subsystems to be positive. This was revealed by marital strain, an increased level of sibling rivalry and the different treatment of children. The sibling subsystem may become disrupted and lose its boundaries as there is possibly more conflict and rivalry than is expected in normal families, and concurs with findings by Spangenberg and Lalkhen (2006). This, in turn, may affect the family structure (Minuchin, 1974) which, in healthy families, should include an intact sibling subsystem. More mothers seemed to take the role of primary caregiver than the fathers did. Furthermore, knowledge about epilepsy made a positive difference to the patients' and family members' functioning and coping. It is noteworthy that the family environment played a major role in the psychological wellbeing of adolescents with epilepsy; this was also demonstrated by Ryu et al. (2015).

6.3 The Family Processes and Coping Strategies of Families of Adolescents Diagnosed with Epilepsy: Integration, Convergence and Divergence of Quantitative and Qualitative Findings

Research question: To what extent and in what ways do the quantitative data from adolescent patients with epilepsy and family members converge with the qualitative results from the family interviews and the GFS?

6.3.1 Differences Between Qualitative and Quantitative Results Within the Patient Group, and Between Patient and Family Groups

An examination of Tables 5.13 and 5.14 reveals the differences between the qualitative and quantitative results within the patient group, and between patient and family groups. The quantitative findings indicated that the younger patients struggled more to adapt and were less satisfied with their families than the older patients. Furthermore, the younger patients had better problem-solving skills than the older patients. The older patients had a greater family identity. Accordingly, the older patients measured higher on the following aspects of family strengths: commitment to promote the growth and wellbeing of the family unit: appreciation of large and small things that family members do well, which they encourage them to do even better at; allocating time for family members to do things together; a sense of purpose that supports the reasons and serves as a foundation to carry on in both good and bad times; and congruence among family members to encourage them to carry on and meet their needs (Dunst et al., 1988). The patients in the lower income group coped better than those in the higher income group. The patients with generalized idiopathic epilepsy and epilepsy syndrome experienced better cohesion in their families than those with other types of epilepsy while all the family members and patients experienced family satisfaction, family functioning, family hardiness and general functioning similarly.

6.3.2 Results Explained from Qualitative Findings

The qualitative findings revealed that the families perceived that the diagnosis affected them more than the patients perceived how it had affected them. These findings emphasize the role of the primary caregiver and the burden of care; this was not evident from the quantitative findings. The qualitative findings also revealed that increasing knowledge about epilepsy and support for families dealing with epilepsy was associated with the patients' and family members' better functioning and coping. In fact, different strategies that the families employed so as to cope with the diagnosis were explored. Furthermore, the qualitative findings indicated the depth of the emotional experience of the diagnosis as well as the depth of the strain on the marital and sibling subsystems. All of this confirms that many factors play a role in the adjustment to the severity of epilepsy, complexity of the clinical management, and the meaning the patient, family and society attributes to the condition. Other aspects found in this study as well as in that of Rood et al. (2014) that play a role include restrictions in the patient and family's activities, the patient and family's' coping abilities, social support and the variety of resources available to deal with the diagnosis.

With respect to similarities, the effect of the diagnosis on the families' emotions was similar regardless of the type of epilepsy. The patients and families faced other challenges as well and both sets of findings revealed that the diagnosis of epilepsy affected the functioning and coping of patients and families.

6.3.3 Summary of Integration of Quantitative and Qualitative Data

In essence, the quantitative findings revealed the following: The 14- to 16-year-old patients had lower adaptability skills and thus, lower family satisfaction than the 17- 18-year-old patients. The family members reported that the families experienced better family functioning than the patients did as well as a greater family identity. The patients reported better general functioning of their families than the family members did. The qualitative findings revealed that the epilepsy diagnosis affected both family members and patients. Most participants were eager to talk about epilepsy and its effects, and seemed to need a platform to do so. Most of the participants indicated that they and their meaningful others needed knowledge and support, and that access to this made a positive meaningful difference.

6.3.4 Convergence of Quantitative- and Qualitative Data

The quantitative and qualitative data complemented each other and created a sense of convergence. The findings of this study give meaningful insight into the family process profiles as reported by the patients and family members.

6.4 Corresponding Experiences of Patients and Family Members

It appears as though the family structure, interactions and relationships changed after the diagnosis of epilepsy. This may be linked to Cousino and Hazen's (2013) study, which found that chronic childhood illnesses often affect the entire family system. Some family members in this study emphasized the hierarchy levels in the families presented by the GFS because the hierarchy levels may have changed due to the epilepsy diagnosis. The data from the interviews and GFSs revealed how the patients' experience the hierarchy levels, and closeness of relationships differed to that of the primary caregiver. The patients appeared to experience it as more distant than that of the parents. This concurs with previous research conducted by Pembroke et al. (2017), which found that initial parental coping patterns form part of how families cope after an initial diagnosis.

The mothers seemed to be more involved with their spouses and the patients than the fathers were. In most of the families, the mother took the role of the primary caregiver. The primary caretaker shouldered a great deal of responsibility regarding the support and treatment after the diagnosis of epilepsy. The data of the interviews and GFSs revealed that the primary caregivers appeared to be overburdened. Existing literature has shown that while mothers typically take up the role as the main caregiver of the adolescent patient, the father's role is perceived as less significant and overlooked by others (Ryu et al., 2015).

To receive a diagnosis of epilepsy and live with it is an emotional experience for patients and family members. It appears as though primary caretakers, in particular, experience negative emotions and allocate these negative emotions to themselves. The patients also perceived that the primary caretakers experienced negative emotions. Primary caretakers are at greater risk for depression (Karakis et al., 2014).

6.5 Other Experiences of Patients and Family Members Derived From the Interviews and GFS

6.5.1 Other Challenges of Participants

The participants also faced other challenges as revealed in the interviews. Epilepsy can result in various psychological implications and challenges, and affects various people such as the patient, family and health care practitioners (Camfield et al., 2017). These challenges include other medical conditions, emotional stressors, relationship difficulties such as marital and among siblings, financial difficulties, divorce and challenges at school.

6.5.2 Distal and Proximal Hope and Communication

The families appeared to go through phases and processes of distal and proximal hope and communication. The findings of Cianchetti et al. (2015) and Zamani et al. (2014) that the quality of life of adolescents with epilepsy was low concur with the findings of the present study. They also found that there is a need to improve psychological health and lower the risk factors that affect the quality of life of adolescents with epilepsy (Cianchetti et al., 2015; Zamani et al., 2014).

6.5.3 Hope and Communication

Some patients outgrow epilepsy; however, even if they do not, family members hope that they will be able to outgrow it. It appears as though this hope encourages them to be compliant with treatment. Communication among family members about epilepsy seemed to make a difference to their coping strategies, while a lack of communication left many unresolved emotions about the diagnosis. Families who communicate with each other, and with the school and treating practitioners, experience better support and understanding on how to cope with the diagnosis (O'Toole et al., 2015). This also includes creating effective communication-based interventions to discuss epilepsy at home. O'Toole et al.'s findings supports the researcher's observation that families who involve the patient in the communication seem to experience more positive functioning and more effective coping strategies than families who do not involve the patient.

6.5.4 Concerns About Health and Future of Patients

The patients did not mention their concerns about their health and future as such. Wood (1996) suggested that chronically ill adolescents must take responsibility for part of their care so as to acquire the ability to manage their illness with responsibility. During the interviews, the family members raised their concern about when the primary caregivers eventually ceased caring for the patients.

6.5.5 Ways to Cope With the Diagnosis

Many families tried to carry on with life as normally as possible while others concentrated on other activities. During the interviews, it became clear that some patients and family members tried to empower themselves with as much knowledge as possible about epilepsy. Furthermore, the researcher noted that it made them feel empowered and possibly more in control. Ferro and Boyle (2013) stated that the diagnosis and seizures tend to make patients and family members feel emotionally out of control and may affect the self-concept of the adolescent with a chronic illness.

6.5.6 Knowledge and Support

It is possible that family members do not realize initially that knowledge and support can make a meaningful effective difference in their functioning (Smith et al., 2014). This concurs with the findings of Veeravigrom, et al. (2013) that revealed that practitioner education, application of an automated tracking system and electronic checklists might improve compliance and patient care. During the interviews, the participants stated that those who have good contact and positive relationships with the school and treating practitioners feel more supported. This links to some extent with the research done by Veeravigrom et al. that revealed that reasons for noncompliance in epilepsy include a lack of clear instructions, misinterpretation of instructions and a lack of proper counselling in relation to safety issues. Some patients attended schools specifically for children with epilepsy; these families perceived that this played a major role in their support.

6.5.7 Feeling Out of Control

The impression that the researcher got from the interviews with the participants is that they felt emotionally out-of-control in the situation, no matter what timespan had lapsed from the patient’s initial diagnosis or last seizure. Research conducted on HIV-positive pregnant women has shown that the first six months after diagnosis might be a critical stage in the coping process and that feelings of being out-of-control reduced significantly over time, with a reduced feeling of being-out-of-control when they received support from health care (Kotzé, Visser, Makin, Sikkema, & Forsyth, 2013). Skinner, Edge, Altman, and Sherwood (2003) found that HIV-positive pregnant women experienced a passive acceptance of an uncontrollable situation shortly after diagnosis. The participants in the present study appeared to have feelings of being out of control regardless of when they were diagnosed with epilepsy; furthermore, these feelings did not necessarily reduce over time. This may be the result of the unpredictable nature of seizures. As noted previously, the researcher chose, as part of the selection criteria, participants who had had a confirmed epilepsy diagnosis for at least six months and whose anti-epileptic medication had stabilized their condition.

6.5.8 Impact on the Family

The findings of this study concur with previous research (Appleton & Gibbs, 2014; Bompori et al., 2014; Cianchetti et al., 2015; O’Toole et al., 2015; Wang et al., 2015; Zebrack et al., 2013) that examined the differences in family processes of families who experience considerable challenges when an adolescent is diagnosed with epilepsy. It seems that families with a child with epilepsy generally fare poorly overall. The whole family is affected by a number of factors such as problems with family functioning, depression in mothers and caregivers, and lower parent-child relationship quality. One parent may become very protective and involved with the sick child and protect him or her from necessary discipline from the other parent. This can cause strain in their marital relationship and place stress on the patient and siblings (Wood, 1996).

A number of specific findings contributed prominently to exploring the family processes and family functioning. First, the unpredictability of the seizures, the patient and family members' fear of feeling out of control and their emotional reactions to the diagnosis posed possible challenges to the processes and functioning of these families. They often reported mixed emotions and symptoms of anxiety and depression. Second, throughout, the families felt that they had very limited knowledge and support structures to deal with the challenges after diagnosis. The continuous feeling of being overwhelmed and losing control led to a decline in their quality of life and contributed to their feelings of emotional and physical burnout; this was especially true for the primary caretakers. The increasing amount of supervision and care needed by the adolescent diagnosed with epilepsy resulted in additional stress, which made further demands on the primary caregivers' energy and time. This occurred at the expense of all the primary caregivers' aspirations, goals and activities that gave their lives meaning. Many primary caregivers reported symptoms of depression.

The qualitative data analysis revealed that on a daily basis these families engaged in a process of adjusting to the diagnosis and in most families, managing to continue life as normally as possible. The researcher observed a number of strengths and coping strategies that contributed significantly to the families' constructive processes and functioning. Examples of these strengths and coping strategies include focusing on communication, including the patient, with support systems. Families tried to carry on with life as normally as possible and concentrated on other activities. Some empowered themselves with knowledge regarding epilepsy.

6.5.9 Experiences Derived from GFS

More of the primary caretakers learned something during the application of the GFS than the patients did; the researcher is of the view that this may be linked to primary caregivers' need to talk about the diagnosis and effect of epilepsy. This need was revealed during the interviews. The GFS enhanced the primary caretakers' understanding and insight about the effect of epilepsy on family functioning. This links with research conducted by the developer of the GFS, which found that during a previous application and interpretation of the GFS, family members acquired new insight and knowledge about the information that they provided (Venter, 1993). The primary caregivers found it easier to represent the family sculptings than the patients did because they had a better understanding of the impact of the diagnosis than the patients did.

6.6 Interpretation of the Participants' Other Characteristics

People in general and treating medical professionals may assume that because most of the patients lived in nuclear families with their married parents that these families functioned well in spite of the diagnosis. This did not appear to be the case. Even if some families have good financial means to pay for medical treatment, this may not guarantee satisfactory emotional functioning. On the other hand, some other families acknowledged that they wished that they had better financial means and thought that it would assist them to function and cope better. Even though the families appeared to be a relatively well-educated group, both the quantitative and qualitative results revealed that this did not enhance their emotional functioning and coping. The researcher also explored the type and severity of epilepsy to examine whether it influenced the family's' functioning and experience. Most of the families were not aware of the patient's formal epilepsy diagnosis, which involved the type of epilepsy. Consequently, the researcher concluded that the diagnosis itself was traumatic for the family, regardless of the type of epilepsy. The mothers of most of the families seemed to be more involved than the fathers and/or other family members. More fathers than mothers in the sample worked full-time and were the family's primary breadwinners. This may explain why more of the mothers were the primary caregivers. Most of the siblings were also adolescents and thus, in the same developmental phase as the patients. This may have caused adjustment difficulties for the families who were facing the challenges of adolescence as well as the diagnosis of epilepsy. It appeared that participating in extra-mural activities played a role in better overall emotional functioning. Therefore, participating in extra-mural activities is recommended for those diagnosed with epilepsy.

6.7 Link findings with paradigmatic position of critical realism and family systems theory

The mixed methods approach applied in this study, which attempted to develop a comprehensive understanding of the phenomenon under investigation, managed to explore the diagnosis of epilepsy of an adolescent through multiple dimensions; thus, making it effective for complex health research (Allana & Clark, 2018; Chiang-Hanisko, Newman, Dyess, Piyakong, & Liehr, 2016). Using a critical realist approach in this mixed methods research justified and supported the use of quantitative- and qualitative methods to explore the family process profiles and experiences of families with an adolescent diagnosed with epilepsy (Zachariadis, Scott, & Barrett, 2013). As this study was not free of values, the critical realism position, with regard to that different realities or truths exist, enabled the researcher to explore the research questions even though the researcher's beliefs, values, theories, hypothesis and background knowledge had an influence on this study (Becvar & Becvar, 2014; Grove, Gray, & Burns, 2015; Wagner et al., 2012). When the researcher conducted interviews, she became part of each family's system by being critical, interpretive and curious. Consequently, the family's embedded reality was investigated and co-constructed by the researcher (Wagner et al., 2012; Willig, 2013). This viewpoint linked critical realism and systems theory.

The researcher looked at the family as a system and at the processes in each family. This is linked to each family's reality that the researcher attempted to understand, even though imperfectly. These families existed as a set of interdependent family members that form an internally organized whole that operates as one in relation to its environment, the reaction to the diagnosis of epilepsy and to other systems, including support systems (Poole, 2014). From the perspective of family systems theory, the researcher focused on acquiring an enhanced understanding of the family's experience by studying the family unit and its circumstances (Becvar & Becvar, 2014; Hauser, 1990). Through the lens of family systems theory, this study could explore more regarding family interactions and relationships rather than on the individual reaction of the patient or a family member. This helped to explain why family members experience the diagnosis of epilepsy as having a huge influence and impact on the functioning and coping of the family (Becvar & Becvar, 2014). It was evident from this study that parental-sibling subsystems play an important role in terms of hierarchy, power, coping and function (Minuchin, 1974).

6.8 Evaluation of the Research

The researcher evaluated the research on her experiences in relation to the paradigmatic and theoretical stance, methodological approach, and personal and epistemological reflexivity as well as how it may have influenced the responses (Todd et al., 2004; Willig, 2013). Critical realism, as the paradigmatic stance, afforded the researcher, through this study, deeper levels of understanding in her exploration of the participants' reality by being able to investigate their multiple outlooks, have better access to their experiences and reality, and attach meaning to their experiences (Halcomb & Hickman, 2015; Pocock, 2015). Employing family systems theory afforded the researcher a view of the experiences and impact of the processes and functioning of the participating families as an interactive whole where the experience of each family member influenced the experience of all the family members (Fleming, 2003; Von Bertanlanffy, 1972). Questionnaires that targeted the family as a whole, which correlated with how systems theories view the family, assisted the collection of quantitative data (Georgiades et al., 2008). It is possible that the representatives of the families answered questions in a manner that reflected their own experiences. These may not necessarily have been a true reflection of all the participating family members' experience. The researcher is of the view that the combination of conducting semi-structured interviews and administering the GFS provided a deeper, more encompassing and enhanced understanding of the experiences and interactions within these families. The interactions of the family members supported the family systems theory approach of examining the family as a functioning system on its own and trying to create balance in the midst of a challenging time when having to deal with the diagnosis of epilepsy. The GFS provided appropriate and insightful meaning from the family systems theoretical approach as it indicated hierarchy systems within the families, boundaries, and more insight into the functioning of the marital and sibling subsystems.

The researcher has extensive interest and experience in psychology in the medical field and has observed that during treatment for medical-related trauma, many themes revolve around patients and their experience in their family during psychotherapy. These themes are related to admission in hospital, their family's support or lack thereof and other unresolved issues within the family.

The mixed-methods approach offered different lenses to capture the different dimensions of the family process profiles of the participants. The quantitative data allowed the researcher the opportunity to compare the experiences of all participants against the same parameters. The qualitative information allowed for in-depth description of the experiences of the participants, which enriched the data as each participant had unique experiences of their family processes and functioning. The data-collection was cost- and time-effective in that it was a once-off data-collection session with each participating family.

A variety of instruments used for the collection of quantitative data enabled an enhanced description of the experiences of the participants. Data collected from both the patients and family members enabled a more in-depth representation of the family's experience as the researcher recognized that the experiences of the patients and their family members could differ.

6.9 Limitations of the Research

The sample was small and the researcher could, therefore, only perform certain quantitative analyses. Although some participants came from rural areas and lower income groups, the scope of this research did not include families who did not have access to a neurologist. The sample consisted of adolescents diagnosed with epilepsy who were receiving treatment from neurologists at private practices in a specific region, namely, Tshwane, which is a typical metropolitan area. Thus, the sample was not representative of all adolescent patients diagnosed with epilepsy in the country.

The subjective nature of self-reporting questionnaires lends itself to questioning the validity of the participants' answers. The participants may have wanted to please the researcher or portray themselves in a better light. The self-report measures could result in some biased responses. A representative of the family had to complete the family questionnaire by consulting with the other family members. This posed a risk in that the family representatives may have chosen to report what they deemed important.

Due to the nature of qualitative research, the data obtained in the qualitative part of the study may be subject to different interpretations by different readers. It was difficult to get all the family members together at the same time. In most instances, mainly the patient and primary caregiver were interviewed. It would be most valuable to get the input of all family members.

The findings explain only a small proportion of the family process profiles that affect the experience of families that live with an adolescent diagnosed with epilepsy.

6.10 Recommendations

The recommendations are divided into implications for practice and recommendations for further research.

6.10.1 Implications for Practice

The systems-therapist has a valuable role in promoting the functioning of these families. When someone is diagnosed with a chronic illness, early intervention can support effective multi-system adjustment and help to prevent destructive maladaptive reaction patterns (Wood, 1996). If the primary caregiver is able to feel empowered and more equipped to deal with the diagnosis from the start, it will have a positive constructive effect overall.

- ***Need to talk about the diagnosis.***

Although patients can be seizure-free with the help of medication, these patients and their family members may not necessarily cope with the diagnosis of epilepsy. Even if seizures are well-controlled, the experience forms part of a long-term process of adjustment to the disease (Austin & Caplan, 2007; Rodenburg et al., 2005). All the participating families had an urgent need to talk about epilepsy and the impact it had on their families. From the themes derived from the data, there appeared to be a discrepancy between the patients' experiences and those of their family members regarding the effective functioning of their families. There was specific strain on marital and sibling relationships and consequently, the families needed support and guidance. Consequently, it is crucial to focus on support for all families and patients and in particular, families with younger patients and families with adolescent patients with other types of epilepsy besides generalized idiopathic epilepsy and epilepsy syndrome need support.

- ***Referral for emotional support.***

It appears that better support, the acquisition of emotional skills and referral for emotional support from the onset of diagnosis may have a positive effect on the functioning and processes of families. Furthermore, the family is a support system to which adolescents can turn when they have fears and uncertainties about themselves and their future (Caprara et al., 2005; Koen et al., 2011). Family therapy may assist in spreading the burden of care so that the primary caregiver does not take on too much responsibility. It appears as though the functioning of the primary caregiver has a considerable influence on the functioning of the families.

Adolescent epilepsy has serious and far-reaching psychosocial consequences and effects for patients and their families. The family members, treating medical specialists and meaningful others in an adolescent's life can play an invaluable role by providing useful knowledge, guidance and support. They can also provide them with an opportunity to share their feelings that cause them to be concerned and worried, without a fear of rejection or minimization of their emotional stressors and suffering. It is recommended that medical specialists refer these families to a psychologist for emotional support after the initial diagnosis and follow-up consultations to determine whether these families make use of extra support. Information leaflets can be compiled and made available to schools, families of patients and medical specialists. A greater awareness regarding the need for emotional support among treating medical specialists may support these families in addressing their needs.

Sometimes a family may have to negotiate with the adolescent patient so as to agree on appropriate restrictions in relation to on the adolescent's activities. In addition, they may face difficult decisions regarding treatment. A team approach with close cooperation between the treating medical specialist, psychologist and family will greatly benefit the outcome of the treatment. Moreover, the treating neurologist should encourage active involvement of the whole family from the outset. Knowledge about epilepsy and its implications, and taking shared responsibility for treatment can promote a sense of control and competency among family members. If families perceive themselves as capable of dealing with the demands and challenges of caregiving and the epilepsy diagnosis, they are likely to experience a better sense of functioning and less stress. It is also important to empower support systems at school and within the community by compiling and providing information leaflets and presenting lectures at schools, which are aimed at learners, parents and teachers (Gazibara et al., 2014). Wang et al. (2015) demonstrated that greater social support received from family members, colleagues, friends and medical personnel is associated with a better quality of life for patients with chronic diseases.

- ***Impact during adolescence.***

During adolescence, family members as well as treating medical specialists may retain too much responsibility for the disease, which may lead to diffuse boundaries. Therefore, it is recommended that treating medical specialists and parents involve patients from the start in taking responsibility for the management of their diagnosis and being involved with consultations held with parents as well. The adolescent patient should take responsibility for taking medication and avoiding possible triggers. However, family members should not hand over responsibility to the adolescent too early before the adolescent is ready to take up this kind of responsibility. They should also ensure that healthy emotional boundaries are respected. According to Wood (1996), when adolescents attempt to rebel during the process of individuation, these patients are likely to rebel against how to manage their illness. This can be prevented if increasing self-care has been included as part of the ongoing treatment from the onset of diagnosis.

- ***Functioning of families***

Primary caregivers need support to spread the burden of care. This is in accordance with as Spangenberg and Lalkhen's (2006) findings. The findings of this study also confirmed those of Rodenburg, Meijer et al. (2005), namely, that the functioning of the family plays a major role in adjustment to illness. The functioning of families in relation to family identity, information sharing and coping needs attention in families like these; accordingly, the family and/or the primary caregiver should be referred for psychological support.

- ***Provide information.***

Healthcare professionals are encouraged to provide information on how to utilize resources within the families' community and work with healthcare practitioners to enhance epilepsy self-management skills; this is in accordance with the findings of Smith et al. (2014). Healthcare practitioners tend to view the medical interview as primarily a data collection exercise in which psychological and social issues are typically avoided (Elliot & Shneker, 2008). Information must be tailored to the circumstances and needs of the adolescent and his or her family and be applicable to the stage of emotional adjustment to the diagnosis of epilepsy. This also concurs with Elliot and Shneker's findings.

Treating medical practitioners play an important role in the adjustment, coping and management of the adolescent with an epilepsy diagnosis and compliance with treatment to ensure a more than satisfactory outcome for patients and healthcare practitioners (Novak et al., 2013). Success at developing better coping and functioning skills seems to depend on the condition itself, the patient that contracted it and the resources available for support.

- ***Personalised medicine.***

A further contribution of the results, based on divergence, is the concept of personalized or systems medicine, which focuses on holism with regard to methods and conceptualization of health and disease (Vogt et al., 2016). This may include disease prevention and health optimization, which can be defined as holistic medicalization (Vogt et al., 2016). This comprises a treatment programme that consists of specific anti-epileptic medication, individual and/or family therapy where necessary and the concept of continuum of care where a multi-disciplinary team of treating specialists can support the specific needs of these families and adjust their help to the various challenges and phases that families may face. This will allow for tailor-made support programmes that are based on the separate needs of the patient and caregiver. Increased knowledge of the factors that might enable these families to maintain their psychological wellbeing, and constructive family processes will not only have a direct impact on patients with epilepsy and care providers, but could also benefit authorities that are responsible for offering support services.

6.10.2 Recommendations for Further Research

Based on the limitations that have been noted as well as the lack of statistical evidence to explain possible tendencies in a larger sample, the researcher is of the view that further research should consider the following recommendations.

- ***Discrepancies between experience of functioning of patients and family members.***

Research and theory stimulated by the current exploration should include a consideration of the discrepancies and convergence between the experience of patients' functioning and that of family members. This findings of this study indicated that patients and family members experience the coping and functioning of the family members differently. It may be interesting and meaningful for these families to explore further specific individual and family differences, and/or to explore why certain differences appear in certain families. Further research could also elaborate on developing programmes on specifically assisting patients and family members in their unique ways of coping and functioning.

- ***Discrepancies between experiences of patients in private practice and patients in government medical settings.***

Further consideration of possible discrepancies between the functioning and processes of families with patients receiving treatment in private practice and in government medical settings may be of interest by employing a larger sample of participants and subsequently, comparing the results between participants receiving treatment in private practice and in government medical settings. It might be that patients receiving treatment in government medical settings might have less practical resources available and further research could explore these discrepancies in order to determine if availability, and the provision of practical resources, could make a difference in their functioning and processes.

- ***Designing, applying and evaluating a support programme.***

It is recommended that further research focus on designing and applying a support programme for families of these patients from the onset of the diagnosis, and to evaluate and monitor their functioning and processes, and compare it with the results of the present study. To apply a support programme such as this successfully, close working and collaboration with neurologists who treat adolescents with epilepsy is recommended. The evaluation of the application of such a support programme, both quantitatively and qualitatively, can provide most valuable feedback.

- ***Follow-up over time.***

It may be interesting to conduct a longitudinal study to explore a family's functioning and processes over time to ascertain whether more enhanced functioning occurs and determine which factors play a role in it. This can assist in exploring whether the duration of the diagnosis does play a role, if families do find ways to cope by themselves, or whether active involvement and support from the start remains invaluable.

- ***Explore whether treating medical practitiioners actually refer families for emotional support.***

Further research could explore whether treating medical practitioners actually do refer these families for emotional support from the onset of diagnosis and compare their results with families who do not receive extra emotional support. It is recommended that observational studies that examine the effects of early intervention and support of families with adolescents diagnosed with epilepsy (beyond self-report) be conducted. Research with this aim can assist in empowering and training of practicing neurologists in better treating their patients holistically, involving the patient's system.

- ***Feedback on follow-up psychotherapy.***

Although the researcher recommended follow-up psychotherapy to many of the families, there was no feedback whether these families made use of the recommendation. A follow-up phone call to the participants is recommended if the study is replicated. Feedback on the type of themes addressed during follow up psychotherapy could also be of interest, to explore whether the theme of epilepsy stays an important factor to deal with during psychotherapy, or whether the space for other themes and aspects that might surface during psychotherapy, need more attention.

- ***Psychological needs and experiences of families..***

The burden of care of epilepsy on family members of an adolescent with epilepsy is a global phenomenon (Solomon & McHale, 2012). When considering the crucial role that these families play, it is evident that research which focuses on their psychological needs and experiences is absolutely imperative. More knowledge about epilepsy and better support for patients and family members may make a significant contribution to enhanced family processes and functioning.

6.11 Conclusion

The study has revealed convincing evidence that families with adolescents diagnosed with epilepsy experience challenges in their processes and functioning. Supporting and empowering these families, especially primary caretakers as they carry a larger burden of care, may strengthen their adjustment to living with the diagnosis of epilepsy. Families are in need of emotional support by meaningful others including larger systems, regardless of the duration or type of epilepsy because patients and their families are affected by the diagnosis and face other challenges as well. It is important to empower treating medical practitioners, meaningful others and the larger society with knowledge so they will be able to support these families. Families, including patients, may not necessarily cope with the diagnosis of epilepsy just because the patient is seizure-free.

Research in the South African context is critical so as to explore the family process profiles of these families as these adolescents are part of the vulnerable youth in the South African context. The involvement and interest of resources in the healthcare system as well as empowerment of these families and their meaningful others including the bigger society may have a positive effect on the outcome, compliance with treatment, appropriate treatment and empowerment of the vulnerable youth of South Africa.

REFERENCE LIST

Aldous, J. (1977). Family interaction patterns. *Annual Review of Sociology, 3*(1)*,* 105-135. doi:10.1146/annurev.so.03.080177.000541

Alexander, J.C. (2014). *Positivism, presupposition and current controversies: Theoretical logic in Sociology*. London, England: Routledge.

Al-Khateeb, J.M., & Al-Khateeb, A.J. (2014). Research on psychosocial aspects of epilepsy in Arab countries: A review of literature. *Epilepsy & Behavior, 31,* 256-262. doi:10.1016/j.yebeh.2013.09.033

Allana, S., & Clark, A. (2018). Applying meta-theory to qualitative and mixed-methods research: A discussion of critical realism and heart failure disease management interventions research. *International Journal of Qualitative Methods, 17*(1), 1-7 doi:10.1177/1609406918790042

Allbright, S.C., Winston, W.L., & Zappe, C.J. (2009). *Data Analysis & Decision Making with Microsoft® Exel,* (3rd ed.) . Mason, OH: South-Western Cengage Learning.

Alyanak, B., Kilinçaslan, A., Kutlu, L., Bozkurt, H., & Aydin, A. (2013). Psychological adjustment, maternal distress, and family functioning in children with obstetrical brachial plexus palsy. *The Journal of Hand Surgery, 38*(1), 137-142. doi:10.1016/j.jhsa.2012.09.036

Amineh, R.J., & Asl, H.D. (2015). Review of constructivism and social constructivism. *Journal of Social Sciences, Literature and Languages, 1*(1), 9-16.

Appleton, R., & Gibbs, J. (2014). *Epilepsy in childhood and adolescence*, (3rd ed.). London, England: CRC Press.

Archer, M., Bhaskar, R., Collier, A., Lawson, T., & Norrie, A. (2013). *Critical realism: Essential readings*. London, England: Routledge.

Årestedt, L., Persson, C., & Benzein, E. (2014). Living as a family in the midst of chronic illness. *Scandinavian Journal of Caring Sciences*, *28*(1), 29-37. doi:10.1111/scs.12023

Atwater, E. (1983). *Adolescence.* Englewood Cliffs, NJ: Prentice-Hall.

Austin, J.K., & Caplan, R. (2007). Behavioral and psychiatric comorbidities in pediatric epilepsy: Toward and integrative model. *Epilepsia, 48*(9), 1639-1651. doi:10.1111/j.1528-1167.2007.01154.x

Baez, T. (2000). *The effects of stress on emotional well-being and resiliency through mediating mechanisms of active coping skills and family hardiness.* (Unpublished doctoral dissertation). Lansing: Michigan State University.

Baldin, E., Hesdorffer, D.C., Caplan, R., & Berg, A.T. (2015). Psychiatric disorders and suicidal behavior in neuro typical young adults with childhood-onset epilepsy. *Epilepsia, 56*(10), 1623-1628. doi:10.1111/epi.13123

Bateson, G. (1979). *Mind and nature: A necessary unity.* New York, NY: Bantam Books.

Bateson, G. (2000). *Steps to an ecology of mind: Collected essays in anthropology, psychiatry, evolution, and epistemology*. University of Chicago Press.

Beavers, W. R. (1977). *Psychotherapy and growth: A family systems perspective*. London, England: Brunner-Routledge.

Becker, S., Bryman, A., & Ferguson, H. (Eds.). (2012). *Understanding research for social policy and social work: themes, methods and approaches*. Oxford, England: Polity Press.

Becvar, D.S. (2007). *Families that flourish: Facilitating resilience in clinical practice.* New York, NY: WW Norton.

Becvar, D.S., & Becvar, R.J. (2014). *Family therapy: A systemic integration* (8th ed.). Essex, England: Pearson.

Becvar, R.J., & Becvar, D.S. (2017). *Systems theory and family therapy: A primer* (3rd ed.). Maryland, MD: Hamilton Books.

Benson, A., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J.K. (2015). “I don’t want them to look at me and think of my illness, I just want them to look at me and see me”: Child perspectives on the challenges associated with disclosing an epilepsy diagnosis to others. *Epilepsy & Behavior, 53,* 83-91. doi:10.1016/j.yebeh.2015.09.026

Benson, A., O’Toole, S., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J.K. (2015). To tell or not to tell: A systematic review of the disclosure practices of children living with epilepsy and their parents. *Epilepsy & Behavior, 51,* 73-95. doi:10.1016/j.yebeh.2015.07.013

Benson, A., O’Toole, S., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J.K. (2016). The stigma experiences and perceptions of families living with epilepsy: Implications for epilepsy-related communication within and external to the family unit. *Patient Education and Counseling, 99*(9), 1473-1481. doi:10.1016/j.pec.2016.06.009

Bergman, M.M. (2010). On concepts and paradigms in mixed methods research. *Journal of Mixed Methods Research, 4*(3), 171–175. doi:10.1177/1558689810376950

Bhaskar, R. (2013). *A realist theory of science*. London, England: Routledge.

Bhaskar, R., Esbjörn-Hargens, S., Hedlund, N., & Hartwig, M. (Eds). (2015). *Metatheory for the twenty-first century: Critical realism and integral theory in dialogue.* London, England: Routledge.

Bihun, J.T., Wamboldt, M.Z., Gavin, L.A., & Wamboldt, F.S. (2002). Can the Family Assessment Device (FAD) be used with school-aged children? *Family Process, 41*(4), 723-731. doi:10.1111/j.1545-5300.2002.00723.x

Bion, W.R. (2003). *Experiences in groups and other papers.* London, England: Routledge.

Bompori, E., Niakas, D., Nakou, I., Siamopoulou-Mavridou, A., & Tzoufi, M.S. (2014). Comparative study of the health-related quality of life of children with epilepsy and their parents. *Epilepsy & Behavior, 41*, 11-17. doi:10.1016/j.yebeh.2014.09.009

Boterhoven de Haan, K.L., Hafekost, J., Lawrence, D., Sawyer, M.G., & Zubrick, S.R. (2015). Reliability and validity of a short version of the general functioning subscale of the McMaster Family Assessment Device. *Family Process*, *54*(1), 116-123. doi:10.1111/famp.12113

Botha, F., & Booysen, F. (2014). Family functioning and life satisfaction and happiness in South African households. *Social Indicators Research, 119*(1), 163-182. doi:10.1007/511205-013-0485-6

Botha, A., Van den Berg, H. S., & Venter, C. A. (2009). The relationship between family-of-origin and marital satisfaction. *Health SA Gesondheid*, *14*(1), 27-34.

Bowen, M. (1976). Theory in the practice of psychotherapy. *Family Therapy: Theory and Practice, 4*(1), 2-90.

Bowen, M. (1985). *Family therapy in clinical practice*. New York, NY: Jason Aronson.

Braun-Lewensohn, O., Idan, O., Lindström, B., & Margalit, M. (2017). Salutogenesis: Sense of coherence in adolescence. In M. Mittelmark et al. (Eds.), *The Handbook of Salutogenesis* (pp. 123-136). Cham, Germany: Springer. doi:10.1007/978-3-319-04600-6_14

Breakwell, G.M., Smith, J.A., & Wright, D.B. (Eds). (2012). *Research methods in psychology* (4th ed.). London, England: Sage.

Brink, H., Van der Walt, C., & Van Rensburg, G. (2006). *Fundamentals of research methodology for health care professionals.* Johannesburg, South Africa: Juta.

Broderick, C.B. (1993). *Understanding family process: Basics of family systems theory.* Thousand Oaks, CA: Sage.

Brody, G. H., & Sigel, I. E. (1990). *Methods of family research: Biographies of research projects, Vol. 2: Clinical populations*. Mahwah, NJ: Lawrence Erlbaum.

Brown, O., Fouche, P., & Coetzee, M. (2010). Bouncing forward: families living with a type I diabetic child. *South African Family Practice*, *52*(6), 536-541.

Brown, A., Talbot, E., Simpson, T., & Whitehouse, W. (2012). Adolescent and parents toolkit (adapt) - self managing psychological concerns of an epilepsy diagnosis: Phase 1 consumer involvement. *Archives of Disease in Childhood*, *97*(1), 138-139.

Burr, V. (1995). *An introduction to social constructionism.* London, England: Routledge.

Burr, V. (1998). Overview: Realism, relativism, social constructionism and discourse. In I. Parker (Ed.), *Social constructionism, discourse and realism* (pp. 13-36). London, England: Sage.

Burr, V. (2018). *Social constructionism.* Singapore, Republic of Singapore: Springer.

Byles, J., Byrne, C., Boyle, M. H., & Offord, D. R. (1988). Ontario Child Health Study: reliability and validity of the general functioning subscale of the McMaster Family Assessment Device. *Family Process*, *27*(1), 97-104.

Camfield, C., Breau, L., & Camfield, P. (2001). Impact of pediatric epilepsy on the family: A new scale for clinical and research use. *Epilepsia, 42*(1), 104-112.

Camfield, C.S., & Camfield, P.R. (2007). Long-term social outcomes for children with epilepsy. *Epilepsia, 48,* 3-5.

Camfield, P.R., & Camfield, C.S. (2014). What happens to children with epilepsy when they become adults? Some facts and opinions. *Pediatric Neurology, 51*(1), 17-23. doi:10/1016/j.pediatrneurol.2014.02.020

Camfield, P., & Camfield, C. (2015). Incidence, prevalence, and etiology of seizures and epilepsy in children. *Epileptic Disorders, 17*(2), 117-123. doi:10/1684/epd.2015.0736

Camfield, P., Camfield, C. Busiah, K., Cohen, D., Pack, A., & Nabbout, R. (2017). The transition from pediatric to adult care for youth with epilepsy: Basic biological, sociological, and psychological issues. *Epilepsy & Behavior, 69*, 170-176. doi:10.1016/j.yebeh.2016.11.009

Caprara, G.V., Pastorelli, C., Regalia, C., Scabini, E., & Bandura, A. (2005). Impact of adolescents' filial self-efficacy on quality of family functioning and satisfaction. *Journal of Research on Adolescence, 15,* 71-97.

Carbone, L., Zebrack, B., Plegue, M., Joshi, S., & Shellhaas, R. (2013). Treatment adherence among adolescents with epilepsy: What really matters? *Epilepsy & Behavior, 27*(1), 59-63. doi:10.1016/j.yebeh.2012.11.047

Carich, M.S., & Willingham, W. (1987). The roots of family systems theory in individual psychology. *Individual Psychology, 43*(1), 71-78.

Carr, A. (2014). The evidence base for family therapy and systemic interventions for child-focused problems. *Journal of Family Therapy, 36*(2), 107-157.

Carter, R. (2014). *The brain book.* London, England: Dorling Kindersley.

Carver, M.D., & Jones, W.H. (1992). The Family Satisfaction Scale. *Social Behavior and Personality: An international journal, 20*(2), 71-84. doi:10.2224/sbp.1992.20.2.71

Cashwell, C.S., & Vacc, N.A. (1996). Familial influences on adolescent delinquent behavior.

Family Journal: Counselling and Therapy for Couples and Families, 4(3), 217-225.

Castro, F.G., Kellison, J.G., Boyd, S.J., & Kopak, A. (2010). A methodology for conducting integrative mixed methods research and data analyses. *Journal of Mixed Methods Research*, *4*(4), 342–360. doi:10.1177/1558689810382916

Chamberlain, K. (2015). Epistemology and qualitative research. *Qualitative Research in Clinical and Health Psychology*, 9-28.

Chiang-Hanisko, L., Newman, D., Dyess, S., Piyakong, D., & Liehr, P. (2016). Guidance for using mixed methods design in nursing practice research. *Applied Nursing Research, 31,* 1-5.

Chilisa, B., & Kawulich, B.B. (2012). Selecting a research approach: Paradigm, methodology and methods. In C. Wagner, B. Kawulich, & M. Garner, *Doing social research: A global context*, (pp. 51-61). London, England: McGraw-Hill.

Chiou, H.H., & Hseih, L.P. (2008). Comparative study of children's self-concepts and parenting stress between families of children with epilepsy and asthma. *Journal of Nursing Research, 16*(1), 65-74.

Choi, H. (2015). Adaptation in families of children with Down syndrome: A mixed-methods design. *Journal of Korean Academy of Nursing, 45*(4)*,* 501-512. doi:10.4040/jkan.2015.45.4.501

Chong, L., Jamieson, N.J., Gill, D., Singh-Grewal, D., Craig, J.C., Ju, A., . . . Tong, A. (2016). Children's experiences of epilepsy: A systematic review of qualitative studies. *Pediatrics, 138*(3)*,* e20160658.

Christian, L.G. (2006). Understanding families: Applying family systems theory to early childhood practice. *Young Children, 61*(1)*,* 12-20.

Cianchetti, C., Messina, P., Pupillo, E., Crichiuttti, G., Baglietto, M.G., Veggiotti, P., . . . Beghi, E. (2015). The perceived burden of epilepsy: Impact on the quality of life of children and adolescents and their families. *Seizure, 24,* 93-101. doi:10.1016/j.seizure.2014.09.003

Cohen, M. M., Tottenham, N., & Casey, B. J. (2013). Translational developmental studies of stress on brain and behavior: Implications for adolescent mental health and illness. *Neuroscience*, *249*, 53-62.

Collins, K. M., Onwuegbuzie, A. J., & Jiao, Q. G. (2006). Prevalence of mixed-methods sampling designs in social science research. *Evaluation & Research in Education*, *19*(2), 83-101. doi:10.2167/eri421.0

Comte, A. (1974). Aim of the course: General considerations on the nature and importance of positive philosophy. In S. Anderski (Ed.), *The essential Comte* (pp. 19-41). London, England: Croom Helm.

Corrigan, F.M., Broome, H., & Dorris, L. (2016). A systematic review of psychosocial interventions for children and young people with epilepsy. *Epilepsy & Behavior, 56,* 99-112. doi:10.1016/j.yebeh.2016.01.005

Cousino, M.K., & Hazen, R.A. (2013). Parenting stress among caregivers of children with chronic illness: A systematic review. *Journal of Pediatric Psychology, 38*(8), 809-828. doi:10.1093/jpepsy/jst049

Crespo, C., Santos, S., Canavarro, M.C., Kielpikowski, M., Pryor, J., & Féres-Carneiro, T. (2013). Family routines and rituals in the context of chronic conditions: A review. *International Journal of Psychology, 48*(5), 729-746. doi:10.1080/00207594.2013.806811

Creswell, J.W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Los Angeles, CA: Sage.

Creswell, J.W. (2015). *A concise introduction to mixed methods research.* Los Angeles, CA: Sage.

Creswell, J.W., & Clark, V.L.P. (2017). *Designing and conducting mixed methods research*. Los Angeles, CA: Sage.

Cruickshank, J. (2012). Positioning positivism, critical realism and social constructionism in the health sciences: A philosophical orientation. *Nursing Inquiry 19*(1), 71-82. doi:10.1111/j.1440-1800.2011.00558.x

Curry, L., & Nunez-Smith, M. (2014). *Mixed methods in health science research: A practical primer* (Vol. 1). Los Angeles, CA: Sage.

Cushner-Weinstein, S., Dassoulas, K., Salpekar, J.A., Henderson, S.E., Pearl, P.L., Gaillard, W.D., & Weinstein, S.L. (2008). Parenting stress and childhood epilepsy: The impact of depression, learning, and seizure-related factors. *Epilepsy &Behavior, 13*(1), 109-114.

Danermark, B., Ekstrom, M., & Jakobsen, L. (2005). *Explaining society: An introduction to critical realism in the social sciences*. London, England: Routledge.

De Boer, H.M., Mula, M., & Sander, J.W. (2008). The global burden and stigma of epilepsy. *Epilepsy & Behavior 12*(4), 540-546.

DeFrain, J., Asay, S.M., & Olson, D.H. (2009). Family functioning. In H.T. Reis and S. Sprecher (Eds.), *Encyclopedia of human relationships* (pp. 622-627). doi:10.4135/9781412958479.n202

Dehn, L.B., Korn-Merker, E., Pfäfflin, M., Ravens-Sieberer, U., & May, T.W. (2014). The Impact on Family scale: Psychometric analysis of long and short forms in parents of children with epilepsy. *Epilepsy & Behavior, 32,* 21-26. doi:10.1016/j.yebeh.2013.12.030

Denscombe, M. (2014). *The good research guide: For small-scale social research projects*. London, England: McGraw-Hill.

Denzin, N.K., & Lincoln, Y.S. (Eds.). (2011). *The SAGE handbook of qualitative research*. London, England: Sage.

De Vos, A. S. (Ed.). (2002). *Research at grass roots: For the social sciences and human services professions*. Cape Town, South Africa: Van Schaik.

Doumit, M. A., & Khoury, M. N. (2017). Facilitating and hindering factors for coping with the experience of having a child with cancer: A Lebanese perspective. *Journal of Psychosocial Oncology*, *35*(3), 346-361.

Dunst, C.J., Trivette, C.M., & Deal, A.G. (1988). *Enabling and empowering families: Principles and guidelines for practice.* Cambridge, England: Brookline Books.

Early, T.J. (2001). Measure for practice with families from a strengths perspective. *The Journal of Contemporary Human Services, 8*(2), 225-232.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, *38*(3), 215-229.

Elliot, J., & Shneker, B. (2008). Patient, caregiver, and health care practitioner knowledge of, beliefs about, and attitudes toward epilepsy. *Epilepsy & Behaviour, 12,* 547-556. doi:10.1016/j.yebeh.2007.11.08

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (2001). Participant observation and fieldnotes. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland (Eds.), *Handbook of ethnography*, (pp. 352-368). London, England: Sage.

Engel, J. (2013). *Seizures and epilepsy* (2nd ed., Vol. 83). New York, NY: Oxford University Press.

Epstein, N.B., Baldwin, L.M., & Bishop, D.S. (1983). The McMaster family assessment device. *Journal of Marital and Family Therapy, 9*(2), 171-180. doi:10.1111/j.1752-0606.1983.tb01497.x

Epstein, R., Ryan, C., Bishop, D., Miller, I., & Keitner, G. (2003). The McMaster model: A view of healthy family functioning. In F. Walsh (Ed.), *Normal family processes: Growing diversity and complexity* (pp. 266-290). London, England: Guilford Press.

Espinola-Nadurille, M., Crail-Melendez, D., & Sánchez-Guzmán, M.A. (2014). Stigma experience of people with epilepsy in Mexico and views of health care providers. *Epilepsy & Behavior, 32,* 162-169. doi:10.1016/j.yebeh.2013.12.007

Faruki, M.A. (2013). Emotional and behavioral disorders in children with epilepsy. *Mymensingh Medical Journal, 22*(2), 313-319.

Ferro, M.A., & Boyle, M.H. (2013). Self-concept among youth with a chronic illness: A meta-analytic review. *Health Psychology, 32*(8), 839-848.

Ferro, M.A., & Boyle, M.H. (2015). The impact of chronic physical illness, maternal depressive symptoms, family functioning, and self-esteem on symptoms of anxiety and depression in children. *Journal of Abnormal Child Psychology, 43*(1), 177-187. doi:10.1007/510802-014-9893-6

Ferro, M.A., Camfield, C.S., Levin, S.D., Smith, M.D., Wiebe, S., Zou, G.Y., & Speechley, K.N. (2013). Trajectories of health-related quality of life in children with epilepsy: A cohort study. *Epilepsia, 54*(11), 1889-1897. doi:10.1111/epi.12388

Ferro, M.A., Ferro, A.L., & Boyle, M.H. (2012). A systematic review of self-concept in adolescents with epilepsy. *Journal of Psychology, 37*(9), 945-958. doi:10.1093/jpepsy/jss076

Fielding, N.G., & Thomas, H. (2008). Qualitative interviewing. In N. Gilbert N. (Ed.) *Researching social life* (3rd ed., pp. 245-265). London, England: Sage.

Fleming, W. M. (2003). Family systems theory. In *International encyclopedia of marriage and family* (2nd ed., Vol. 2, pp. 642–646). New York, NY: Macmillan Reference USA.

Fletcher, A.J. (2017). Applying critical realism in qualitative research: Methodology meets method. *International Journal of Social Research Methodology, 20*(2), 181-194. doi:10.1080/13645579.2016.1144401

Flick, U. (2018). *An introduction to qualitative research*. Los Angeles, CA: Sage.

Forrester, M. A., & Sullivan, C. (Eds.). (2018). *Doing qualitative research in psychology: A practical guide*. Los Angeles, CA: Sage.

Friedman, E.H. (1986). Emotional process in the marketplace: The family therapist as consultant with work systems. In L. Wynne, S. McDaniel, & T. Weber (Eds.). *Systems consultation: A new perspective for family therapy,* (p. 398). New York, NY: Guilford Press.

Frost, N. (2011). *Qualitative research methods in psychology: Combining core approaches*. London, England: McGraw-Hill.

Gabr, W.M., & Shams, M.E.E. (2015). Adherence to medication among outpatient adolescents with epilepsy. *Saudi Pharmaceutical Journal, 23*(1), 33-40. doi:10.1016/j.jsps.2014.05.003

Gabriel, R., Figueiredo, D., Jácome, C., Cruz, J., & Marques, A. (2014). Day-to-day living with severe chronic obstructive pulmonary disease: Towards a family-based approach to the illness impacts. *Psychology & Health, 29*(8), 967-983. doi:10.1080/08870446.2014.902458.

Gazibara, T., Nikolovski, J., Lakic, A., Pekmezovic, T., & Kisic-Tepavcevic, D. (2014). Parental knowledge, attitudes, and behaviors towards children with epilepsy in Belgrade (Serbia). *Epilepsy & Behavior, 41,* 210-216. doi:10.1016/j.yebeh.2014.09.062

Gebauer-Bukurov, K., Markovic, J, Sekulic, S., & Bozic, K. (2015). Social competence among well-functioning adolescents with epilepsy. *Epilepsy & Behavior, 42,* 54-60. doi:10.1016/j.yebeh.2014.11.004

Geerlings, R.P.J., Aldenkamp, A.P., De With, P.H.N., Zinger, S., Gottmer-Welschen, L.M.C., & De Louw, A.J.A. (2015). Transition to adult medical care for adolescents with epilepsy. *Epilepsy & Behavior, 44,* 127-135. doi:10.1016/j.yebeh.2014.12.041

Geerlings, R.P.J., Aldenkamp, A.P., Gottmer-Welschen, L.M.C., De With, P.H.N., Zinger, S., Van Staa, A.L., & De Louw, A.J.A. (2015). Developing from child to adult: Risk factors for poor psychosocial outcome in adolescents and young adults with epilepsy. *Epilepsy & Behavior, 51,* 182-190. doi:10.1016/j.yebeh.2015.07.035

Geerlings, R.P.J., Aldenkamp, A.P., Gottmer-Welschen, L.M.C., De With, P.H.N., Zinger, S., Van Staa, A.L., & De Louw, A.J.A. (2016). Evaluation of a multidisciplinary epilepsy transition clinic for adolescents. *European Journal of Paediatric Neurology, 20,* 385-392. doi:10.1016/j.ejpn.2016.01.003

Georgiades, K., Boyle, M.H., Jenkins, J.M., Sanford, M., & Lipman, E. (2008). A multilevel analysis of whole family functioning using the McMaster Family Assessment Device. *Journal of Family Psychology, 22*(3), 344-354.

Gergen, K.J. (1998). Constructionism and realism: How are we to go on? In I. Parker (Ed.), *Social constructionism, discourse and realism.* London, England: Sage.

Giddens, A. (2013). *Politics, sociology and social theory: Encounters with classical and contemporary social thought.* Oxford, England: Polity Press.

Goldenberg, H., & Goldenberg, I. (2013). *Family therapy: An overview* (8th ed.). Melborne, Australia: Brooks/Cole.

Greef, A.P., & Van der Merwe, S. (2004). Variables associated with resilience in divorced families. *Social Indicators Research, 68,* 59-75.

Greeff, A.P., Vansteenwegen, A., & Geldhof, A. (2014). Resilience in families with a child with cancer. *Pediatric Hematology and Oncology, 31*(7), 670-679. doi:10.3109/08880018.2014.905666

Green, S.B., & Salkind, N.J. (2008). *Using SPSS for Window and Macintosh: Analyzing and understanding data* (5th ed.). Upper Saddle River, NJ: Pearson Prentice Hall.

Groff, R. (2004). *Critical realism, post-positivism, and the possibility of knowledge.* London, England: Routledge.

Grove, S.K., Gray, J.R., & Burns, N. (2015). *Understanding nursing research: Building an evidence-based practice* (6th ed.). Missouri, MO: Elsevier Saunders.

Haefner, J. (2014). An application of Bowen family systems theory. *Issues in Mental Health Nursing, 35*(11). doi:10.3109/01612840.2014.921257.

Halcomb, E.J., & Hickman, L. (2015). Mixed methods research. *Nursing Standard: Promoting Excellence in Nursing Care, 29*(32), 41-47.

Hanson, B.G. (2013). *General systems theory beginning with wholes*. London, England: Routledge.

Harden, J., Black, R., & Chin, R.F.M. (2016). Families' experiences of living with pediatric epilepsy: A qualitative systematic review. *Epilepsy & Behavior, 60,* 225-237. doi:10.1016/j.yebeh.2016.04.034

Hartwig, M. (2007). *Dictionary of critical realism.* London, England: Routledge.

Hatzipapas, I., Visser, M.J., & Janse van Rensburg, E.J. (2017). Laughter therapy as an intervention to promote psychological well-being of counter community care workers working with HIV-affected families. *SAHARA-J: Journal of Social Aspects of HIV/AIDS, 14*(1), 202-212.

Hauser, S.T. (1990). The study of families and chronic illness: Ways of coping and interacting. In G.H. Brody, and I.E. Sigel (Eds.), *Methods of family research: Biographies of research projects, 2,* (pp. 59-86). New Jersey, NJ: Lawrence Erlbaum.

Hecimovic, H., Santos, J.M., Carter, J., Attarian, H.P., Fessler, A.J., Vahle, V., & Gilliam, F. (2012). Depression but not seizure factors or quality of life predicts suicidality in epilepsy. *Epilepsy & Behavior, 24*(4), 426-429. doi:10.1016/j.yebeh.2012.05.005

Heijnders, M., & Van Der Meij, S. (2006). The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychology, Health & Medicine, 11*(3), 353-363. doi:10.1080/13548500600595327

Henwood, K. (2014). Qualitative research. *Encyclopedia of Critical Psychology*, 1611-1614.

Hoare, P., & Kerley, S. (1992). Helping parents and children with epilepsy cope successfully: The outcome of a group programme for parents. *Journal of Psychosomatic Research*, *36*(8), 759-767.

Hsiao, C.Y. (2014). Family demands, social support and family functioning in Taiwanese families rearing children with Down syndrome. *Journal of Intellectual Disability Research, 58*(6), 549-559. doi:10.1111/jir.12052

Hsiao, C.Y., Tsai, Y.F. (2015). Factors of caregiver burden and family functioning among Taiwanese family caregivers living with schizophrenia. *Journal of Clinical Nursing, 24*(11-12), 1546-1556. doi:10.1111/jocn.12745

Imran, A., & Yusoff, R.M. (2015). Empirical validation of qualitative data: A mixed method approach. *International Journal of Economics and Financial Issues, 5*(1), 389-396.

Irvine, A., Drew, P., & Sainsbury, R. (2013). 'Am I not answering your questions properly?' Clarification, adequacy, and responsiveness in semi-structured telephone and face-to-face interviews. *Qualitative Research 13*(1) 87–106. University of York, England: Sage. doi:10.1177/1468794112439086

Iseri, P.K., Ozten, E., & Aker, A.T. (2006). Posttraumatic stress disorder and major depressive disorder is common in parents of children with epilepsy. *Epilepsy & Behavior, 8,* 250-255.

Israel, M., & Hay, I. (2006). *Research ethics for social scientists: Between ethical conduct and regulatory compliance*. Thousand Oaks, CA: Sage.

Jacoby, A., Snape, D., & Baker, G.A. (2005). Epilepsy and social identity: The stigma of a chronic neurological disorder. *The Lancet: Neurology, 4*(3), 171-178.

Jeong, A., Shin, D.W., Kim, S.Y., Yang, H.K. Shin, J.Y., Park, K., . . . Park, J. (2016). The effects on caregivers of cancer patients' needs and family hardiness. *Psycho-Oncology, 25*(1), 84-90. doi:10.1002/pon.3878

Joachim, G.L., & Acorn, S. (2016). Living with chronic illness: The interface of stigma and normalization. *Canadian Journal of Nursing Research Archive, 32*(3), 1-7.

Johnson, N.L., & Simpson, P.M. (2013). Lack of father involvement in research on children with autism spectrum disorder: Maternal parenting stress and family functioning. *Issues in Mental Health Nursing, 34*(4), 220-228. doi:10.3109/01612840.2012.745177

Johnson, R.B., & Onwuegbuzie, A.J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher, 33*(7), 14-26.

Jones, C., & Reilly, C. (2016). Parental anxiety in childhood epilepsy: A systematic review. *Epilepsia, 57*(4), 529-537. doi:10.111/epi.13326

Jonsson, P., Jonsson, B., & Eeg-Olofsson, O. (2014). Psychological and social outcome of epilepsy in well-functioning children and adolescents. A 10-year follow-up study. *European Journal of Paediatric Neurology, 18*(3), 381-390. doi:10.1016/j.ejpn.2014.01.010

Karakis, I., Cole, A.J., Montouris, G.D., San Luciano, M., Meador, K.J., & Piperidou, C. (2014). Caregiver burden in epilepsy: Determinants and impact. *Epilepsy Research and Treatment.* doi:10.1155/2014/808421

Keeney, B.P. (1981). Bateson's epistemology. *Journal of Strategic and Systemic Therapies,* (1)*,* 45-55.

Keeney, B.P. (2017). *Aesthetics of change.* New York, NY: Guilford Press.

Keeney, B.P., & Ross, J.M. (1983). Cybernetics of brief family therapy. *Journal of Marital and Family Therapy, 9*(4)*,* 375-382.

Keeney, B.P., & Ross, J.M. (1985). *Mind in therapy: Constructing systemic family therapies.* New York, NY: Basic Books.

Kelly, G.A. (1955). *The psychology of personal constructs, Volume 1: A theory of personality.* New York, NY: WW Norton.

Kendall-Taylor, N., Kathomi, C., Rimba, K., & Newton, C. R. (2009). Family well-being and children with epilepsy in Kilifi, Kenya: "When a child convulses his family is affected". *Open Family Studies Journal*, *2*, 54-65.

Kerne, V., & Chapieski, L. (2015). Adaptive functioning in pediatric epilepsy: Contributions of seizure-related variables and parental anxiety. *Epilepsy & Behavior, 43,* 48-52. doi:10.1016/j.yebeh.2014.11.030

Kerr, C., Nixon, A., & Wild, D. (2010). Assessing and demonstrating data saturation in qualitative inquiry supporting patient reported outcomes research. *Expert Review of Pharmacoeconomics & Outcomes Research, 10*(3), 269–281.

Khan, A., Baheerathan, A., Hussain, N., & Whitehouse, W. (2013). Transition of children with epilepsies to adult care. *Acta Paediatrica, 102*(3), 216-221. doi:10.1111/apa.12097 Knafl, K.A., Deatrick, J.A., Knafl, G.J., Gallo, A.M., Grey, M., & Dixon, J. (2013). Patterns of family management of childhood chronic conditions and their relationship to child and family functioning. *Journal of Pediatric Nursing, 28*(6), 523-535. doi:10.1016/j.pedn.2013.03.006

Koen, V. (2009). *The parent-adolescent relationship and the emotional wellbeing of adolescents.* (Unpublished master's thesis). North-West University, Potchefstroom, South Africa.

Koen, V. (2012). *Family psychosocial well-being in a South African context.* (Unpublished doctoral dissertation). North-West University, Potchefstroom, South Africa.

Koen, V., Van Eeden, C., & Venter, C. (2011). African female adolescents' experience of parenting and their sense of well-being. *Journal of Psychology in Africa, 21*(2), 197-210. Kolahi, A. A., Abbasi-Kangevari, M., Bakhshaei, P., Mahvelati-Shamsabadi, F., Tonekaboni,

S. H., & Farsar, A. R. (2017). Knowledge, attitudes, and practices among mothers of children with epilepsy: A study in a teaching hospital. *Epilepsy & Behavior*, *69*, 147-152. Kolakowski, L. (1972). *Positivist philosophy: From Hume to the Vienna Circle.* London, England: Penguin.

Kotzé, M., Visser, M., Makin, J., Sikkema, K., & Forsyth, B. (2013). The coping strategies used over a two-year period by HIV-positive women who had been diagnosed during pregnancy. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV, 25*(6), 695-701.

Lambert, V., & Keogh, D. (2015). Striving to live a normal life: A review of children and young people's experience of feeling different when living with a long term condition. *Journal of Pediatric Nursing, 30*(1), 63-77. doi:10.1016/j.pedn.2014.09.016

Laszlo, E. (1996). *The systems view of the world: A holistic vision for our time (Advances in systems theory, complexity, and the human sciences).* New York, NY: George Braniller.

Lederer, W. J., & Jackson, D. D. (1968). *The mirages of marriage*. New York, NY: Norton.

Lewis, S. (2015). Qualitative inquiry and research design: Choosing among five approaches. *Health Promotion Practice*, *16*(4), 473-475.

Lewis, M. A., Hatton, C. L., Salas, I., Leake, B., & Chiofalo, N. (1991). Impact of the children's epilepsy program on parents. *Epilepsia*, *32*(3), 365-374.

Lim, J.W., & Ashing-Giwa, K.T. (2013). Is family functioning and communication associated with health-related quality of life for Chinese- and Korean-American breast cancer survivors? *Quality of Life Research, 22*(6), 1319-1329. doi:10.1007/511136-012-0247y

Lincoln, Y. S., & Guba, E. G. (2013). *The constructivist credo*. Walnut creek, CA: Left Coast Press.

Loga Andrijić, N., Alajbegović, A., Loga Zec, S., & Loga, S. (2014). Suicidal ideation and thoughts of death in epilepsy patients. *Psychiatria Danubina, 26*(1), 52-55.

Lopez, S.J., Pedrotti, J.T., & Snyder, C.R. (2018). *Positive psychology: The scientific and practical explorations of human strengths* (4th ed.). Los Angeles, CA: Sage.

Losch, A. (2009). On the origins of critical realism. *Theology and Science*, *7*(1), 85-106. doi:10.1080/14746700802617105

Luhmann, N. (2013). *Introduction to systems theory.* Cambridge, England: Polity Press.

Lv, R., Wu, L., Jin, L., Lu, Q., Wang, M., Qu, Y., & Liu, H. (2009). Depression, anxiety and quality of life in parents of children with epilepsy. *Acta Neurologica Scandinavica*, *120*(5), 335-341. doi:10.1111/j.1528-1167.2011.03094.x

Maiga, Y., Albakaye, M., Diallo, L.L., Traoré, B., Cissoko, Y., Hassane, S., . . . Carmant, L. (2014). Current beliefs and attitudes regarding epilepsy in Mali. *Epilepsy & Behavior, 33,* 115-121. doi:10.1016/j.yebeh.2014.02.031

Mansfield, A.K., Keitner, G.I., & Dealy, J. (2015). The Family Assessment Device: An update. *Family Process, 54*(1), 82-93. doi: 10.1111/famp.12080

Marchetti-Mercer, M.C., & Cleaver, G. (2000). Genograms and family sculpting: An aid to cross-cultural understanding in the training of psychology students in South Africa. *The Counselling Psychologist, 28*(1)*,* 61-80.

Masten, A.S., & Reed, M.G.J. (2005). Resilience in development. In C.R. Snyder & S.J. Lopez (Eds.), *Handbook of Positive Psychology* (pp. 78-88). New York, NY: Oxford University Press.

Maturana, H.R., & Varela, F.J. (1987). *The tree of knowledge: Biological roots of human understanding.* London, England: New Science Library/Shambhala Publications.

McCubbin, M.A., & McCubbin, H.I., & Thompson, A.I. (1996). Family Hardiness index (FHI). In H.I. McCubbin, A.I. Thompson, & M.A. McCubbin*. Family assessment: Resiliency, coping and adaptation – Inventories for research and practice* (pp. 239-305). Madison: University of Wisconsin.

McCubbin, M.A., McCubbin, H.I., & Thompson, A.I. (1991). FHI Family Hariness index. In H.I. McCubbin, & A.I. Thompson (Eds.). *Family assessment inventories for research and practice* (pp.127-136). Madison: University of Wisconsin.

McCubbin, H. I., & Thompson, A. I. (1991). *Family stress coping and health project*. Madison: University of Wisconsin-Madison.

McCubbin, H. I., Thompson, A. I., Pirner, P. A., & McCubbin, M. A. (1988). *Family types and strengths: A life cycle and ecological perspective*. Edina, MN: Burgess International Group.

McEwan, L., Taylor, J., Casswell, M., Entwistle, R, Jacoby, K., Gorry, J., . . . Baker, G.A. (2007). Knowledge of and attitudes expressed toward epilepsy by carers of people with epilepsy: A UK perspective. *Epilepsy & Behavior, 11*(1), 13-19.

Miklowitz, D. (1994). Family systems. In V.S. Ramachandran (Ed.) *Encyclopedia of Human Behavior 2*, 371-379. San Diego, CA: Academic Press.

Minuchin, S. (1974). *Families and family therapy.* Cambridge, England: Harvard University Press.

Mishra, O. P., Upadhyay, A., Prasad, R., Upadhyay, S. K., & Piplani, S. K. (2017). Behavioral problems in Indian children with epilepsy. *Indian Pediatrics*, *54*(2), 116-120. doi:10.1007/513312-017-1012-7

Moore, S.M., Hackworth, N.J. Hamilton, V.E., Northam, E.P., & Cameron, F.J. (2013). Adolescents with Type 1 Diabetes: Parental perceptions of child health and family functioning and their relationship to adolescent metabolic control. *Health and Quality of Life Outcomes, 11*(1),1.

Moshé, S.L., Perucca, E. Ryvlin, P., & Tomson, T. (2015). Epilepsy: New advances. *The Lancet, 385*(9971), 884-898. doi:10.1016/S0140-6736(14)60456-6

Mu, P.F. (2008). Transition experience of parents caring of children with epilepsy: A phenomenological study. *International Journal of Nursing Studies, 45*(4), 543-551. doi:10.1016/j.ijnurstu.2006.10.009

Mu, P.F., & Chang, K.P. (2010). The effectiveness of a program of enhancing resiliency by reducing family boundary ambiguity among children with epilepsy. *Journal of Clinical Nursing, 19*(9-10), 1443-1453. doi:10.1111/j.1365-2702.2009.03075.x

Murugupillai, R., Wanigasinghe, J., Muniyandi, R., & Arambepola, C. (2016). Parental concerns towards children and adolescents with epilepsy in Sri Lanka – Qualitative study. *Seizure, 34,* 6-11. doi:10.1016/j.seizure.2015.10.016

Mustapha, A.F., Odu, O.O., & Akande, O. (2013). Knowledge, attitudes, and perceptions of epilepsy among secondary school teachers in Osogbo South-West Nigeria: A community based study. *Nigerian Journal of Clinical Practice, 16*(1), 12-18. doi:10.4103/1119-3077.106709

Nabbout, R., Andrade, D.M., Bahi-Buisson, N., Cross, H., Desquerre, I., Dulac, O., . . . Camfield, C.S. (2017). Outcome of childhood-onset epilepsy from adolescence to adulthood: Transition issues. *Epilepsy & Behavior, 69,* 161-169. doi:10.1016/j.yebeh.2016.11.010

Nabbout, R., Camfield, C.S., Andrade, D.M., Arzimanoglou, A., Chiron, C., Cramer, J.A., .. Camfield, P.R. (2017). Treatment issues for children with epilepsy transitioning to adult care. *Epilepsy & Behavior, 69,* 153-160. doi:10.1016/j.yebeh.2016.11.008

Nabors, L.A., Kichler, J.C., Brassel, A., Thakkar, S., Bartz, J., Pangallo, J., . . . Lundy, H. (2013). Factors related to caregiver state anxiety and coping with a child's chronic illness. *Families, Systems, & Health, 31*(2), 171-180.

Neuman, W.L. (2014). *Social research methods: Qualitative and quantitative approaches*

(3rd ed.). Boston, MA: Allyn and Bacon.

Newton, N. (2010). The use of semi-structured interviews in qualitative research: Strengths and weaknesses. *Exploring Qualitative Methods, 1*(1), 1-11.

Nichols, M.P. (2010). *Family therapy: Concepts and methods* (9th ed.). Boston, MA: Allyn & Bacon.

Noble, A. J., Morgan, M., Virdi, C., & Ridsdale, L. (2013). A nurse-led self-management intervention for people who attend emergency departments with epilepsy: The patients' view. *Journal of Neurology*, *260*(4), 1022-1030.

Novak, M., Costantini, L., Schneider, S., & Beanlands, H. (2013). Approaches to self-management in chronic illness. In *Seminars in Dialysis, 26*(2), 188-194. Oxford, England: Blackwell Publishing. doi:10.1111/sdi.12080

Novick, G. (2008). Is there a bias against telephone interviews in qualitative research? *Research in Nursing and Health 31*(4), 391–398.

Olson, D.H. (2002). Circumplex model of marital and family systems. *Journal of Family Therapy, 22*(2), 144-167. doi:10.1111/1467-6427.00144

Olson, D.H. (2010). *Family Satisfaction Scale*. Minneapolis, MN: Life Innovations.

Olson, D.H. (2012). Circumplex model of marital and family systems: Assessing family functioning. In F. Walsh (Ed.). *Research on normal family processes* (pp. 104-134). New York, NY: Guilford Press.

Olson, D.H., & Gorall, D.M. (2003). Circumplex Model of marital and family systems. In F. Walsh (Ed.). *Normal family processes*, (3rd ed., pp. 514-547). New York, NY: Guilford Press.

Olson, D. H., Russell, C. S., & Sprenkle, D. H. (1983). Circumplex model of marital and family systems: VI. Theoretical update. *Family Process*, *22*(1), 69-83.

Olson, D., Russell, C. S., & Sprenkle, D. H. (2014). *Circumplex model: Systemic assessment and treatment of families*. London, England: Routledge.

Olson, D.H., & Wilson, M. (1982). Family satisfaction. In D.H. Olson, H.I. McCubbin, H. Barnes, A. Larsen, M. Muxen, & M. Wilson (Eds.), *Family Inventories: Inventories used in a national survey of families across the family life cycle* (pp. 25-31). St Paul, MN: University of Minnesota.

Onwuegbuzie, A.J., & Leech, N.L. (2004). Enhancing the interpretation of significant findings: The role of mixed-methods research. *The Qualitative Report 9*(4), 770-792.

Onwuegbuzie, A. J., & Leech, N. L. (2005). Taking the "Q" out of research: Teaching research methodology courses without the divide between quantitative and qualitative paradigms. *Quality and Quantity*, *39*(3), 267-295.

O'Toole, S., Benson, A., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J.K. (2015). Family communication in the context of pediatric epilepsy: A systematic review. *Epilepsy & Behavior, 51,* 225-239. doi:10.1016/j.yebeh.2015.06.043

Papalia, D., Martorell, G., & Feldman, R. (2014). *A child's world: Infancy through adolescence,* (13th ed.). Dubuques, Iowa: McGraw-Hill.

Pembroke, S., Higgins, A., Pender, N., & Elliott, N. (2017). Becoming comfortable with "my" epilepsy: Strategies that patients use in the journey from diagnosis to acceptance and disclosure. *Epilepsy & Behavior, 70*(A), 217-223. doi:10/1016/j.yebeh.2017.02.001

Perucca, E. (2016). Medical management. In S. Shorvon, E. Perucca, & J. Engel (Eds.). *The treatment of epilepsy* (4th ed., pp. 110-123). West Sussex, England: John Wiley & Sons.

Peterson, R., & Green, S. (2009). Families first: Keys to successful family functioning. *Communication*. Retrieved from http://www.pubs.ext.vt.edu/350/350-092/350-092.html Pillay, A.L., & Wassenaar, D.R. (1997). Recent stressors and family satisfaction in suicidal adolescents in South Africa. *Journal of Adolescence, 20*(2)*,* 155-162.

Pocock, D. (2015). A philosophy of practice for systemic psychotherapy: The case for critical realism. *Journal of Family Therapy, 37*(2), 167-183. doi:10.1111/1467-6427.12027

Polit, D.F., & Hungler, B.P. (1987). *Nursing research: Principles and methods* (3rd ed.). Philadelphia, PA: Lippincott.

Polit, D.F., & Beck, C.T. (2004). *Nursing research: Principles and methods*. Philadelphia, PA: Lippincott Williams & Wilkens.

Poole, M. S. (2014). Systems theory. In L.L. Putnam, & D.K. Mumby (Eds.), *The SAGE handbook of organizational communication: Advances in theory, research, and methods* (pp. 49- 74). Los Angeles, CA: Sage.

Popp, J.M., Robinson, J.L., Britner, P.A., & Blank, T.O. (2014). Parent adaptation and family functioning in relation to narratives of children with chronic illness. *Journal of Pediatric Nursing, 29*(1), 58-64. doi:10.1016/j.pedn.2013.07.004

Preto, N.G. (2011). Transforming of the family system during adolescence. In M. McGoldrick, B. Carter, & N. Garcia-Preto (Eds.). *Individual, family, and social perspectives: The expanded family life cycle* (pp. 232-246). Boston, MA: Allyn & Bacon. Puka, K., Widjaja, E., & Smith, M.L. (2017). The influence of patient, caregiver, and family factors on symptoms of anxiety and depression in children and adolescents with intractable epilepsy. *Epilepsy & Behavior, 67,* 45-50. doi:10.1016/j.yebeh.2016.12.011

Räty, L.K., & Wilde-Larsson, B.M. (2011). Patients' perceptions of living with epilepsy: A phenomenographic study. *Journal of Clinical Nursing, 20*(13-14), 1993-2002.

Reilly, C., Kent, E., & Neville, B.G.R. (2013). Psychopathology in childhood epilepsy. *Child and Adolescent Mental Health, 18*(2), 65-75. doi:10.1111/j.1475-3588.2012.00648

Robinson, M.B. (2003). *Family Hardiness Index: Methodology for use with children* (Doctoral dissertation). Retrieved from http://search.proquest.com/docview/305311644? accountid=14717

Rodenburg, R., Meijer, A.M., Deković, M., & Aldenkamp, A.P. (2005). Family factors and psychopathology in children with epilepsy: A literature review. *Epilepsy & Behavior 6*(4), 488-503. doi:10.1016/j.yebeh.2005.03.006

Rodenburg, R., Meijer, A.M., Dekovic, M., & Aldenkamp, A.P. (2007). Parents of children with enduring epilepsy: Predictors of parenting stress and parenting. *Epilepsy & Behavior, 11*(2), 197-207. doi:10.1016/j.yebeh.2007.05.001

Rodenburg, R., Meijer, A.M., Scherphof, C., Carpay, J.A., Augustijn, P., Aldenkamp, A.P., & Deković, M. (2013). Parenting and restrictions in childhood epilepsy. *Epilepsy & Behavior, 27*(3), 497-503. doi:10.1016/j.yebeh.2013.01.026

Rodenburg, R., Stams, G.J., Meijer, A.M., Aldenkamp, A.P., & Deković, M. (2005). Psychopathology in children with epilepsy: A meta-analysis. *Journal of Pediatric Psychology, 30*(6), 453-468. doi:10.1093/jpepsy/jsi071

Rodenburg, R., Wagner, J.L., Austin, J.K., Kerr, M., & Dunn, D.W. (2011). Psychosocial issues for children with epilepsy. *Epilepsy & Behavior, 22*(1), 47-54. doi:10.1016/j.yebeh.2011.04.063

Rolland, J.S. (2011). Chronic illness and the life cycle. In M. McGoldrick, B. Carter, & N. Garcia-Preto (Eds.), *Individual, family, and social perspectives: The expanded family life cycle* (pp. 232-246). Boston, MA: Allyn & Bacon.

Rood, J.E., Schultz, J.R., Rausch, J.R., & Modi, A.C. (2014). Examining perceived stigma of children with newly-diagnosed epilepsy and their caregivers over a two-year period. *Epilepsy & Behavior, 39,* 39-41. doi:10.1016/j.yebeh.2014.08.004

Roux, P.W. (1997). *The family process of high school underachievers*. (Unpublished masters thesis). North-West University, Potchefstroom, South Africa.

Ryan, C. E., Epstein, N. B., Keitner, G. I., Miller, I. W., & Bishop, D. S. (2012). *Evaluating and treating families: The McMaster approach*. London, England: Routledge.

Ryan, C.E., & Keitner, G.I. (2009). Family functioning assessment in rehabilitation and health. In E. Mpofu & T. Oakland (Eds.), *Assessment in rehabilitation and health,* (pp. 486-502). Upper Saddle River, NJ: Pearson.

Rychlak, J.F. (1973). *Introduction to personality and psychotherapy: A theory-construction approach.* Boston, MA: Houghton Mifflin.

Ryu, H. U., Lee, S.A., Eom, S., Kim, H.D., & Korean QoL in Epilepsy Study Group. (2015). Perceived stigma in Korean adolescents with epilepsy: Effects of knowledge about epilepsy and maternal perception of stigma. *Seizure, 24,* 38-43. doi:10.1016/j.seizure.2014.11.010

Sadock, B.J., & Sadock, V.A. (2007). *Kaplan and Sadock's synopsis of psychiatry: Behavioral sciences, clinical psychiatry* (10th ed.). Philadelphia, PA: Lippincott Williams & Wilkens.

Santos, J. L. G. D., Erdmann, A. L., Meirelles, B. H. S., Lanzoni, G. M. D. M., Cunha, V. P. D., & Ross, R. (2017). Integrating quantitative and qualitative data in mixed methods research. *Texto & Contexto-Enfermagem*, *26*(3), 288-296. doi:10.1590/0104-07072017001590016

Scherz, F.H. (1962). Multiple-client interviewing: Treatment implications. *Social Casework, 43*(3), 120-125.

Schraegle, W.A., & Titus, J.B. (2017). The relationship of seizure focus with depression, anxiety, and health-related quality of life in children and adolescents with epilepsy.

Epilepsy & Behavior, 68, 115-122. doi:10.1016/j.yehbeh.2016.12.009

Schuler, T.A., Zaider, T.I., Li, Y., Hichenberg, S., Masterson, M., & Kissane, D.W. (2014). Typology of perceived family functioning in an American sample of patients with advanced cancer. *Journal of Pain and Symptom Management, 48*(2), 281-288. doi:10.1016/j.jpainsymman.2013.09.013

Segrin, C., & Flora, J. (2011). *Family communication.* London, England: Routledge.

Seligman, M., & Darling, R.B. (2007). *Ordinary families, special children: A systems approach to childhood disability* (3rd ed). New York, NY: Guilford Press.

Shek, D.T. (1998). A longitudinal study of Hong Kong adolescents' and parents' perception of family functioning and well-being. *The Journal of Genetic Psychology*, *159*(4), 389-403.

Shorvon, S. (2016). Definition and classification. In S. Shorvon, E. Perucca, & J. Engel. *The treatment of epilepsy* (4th ed., Chapter 1). West Sussex, England: John Wiley & Sons.

Shorvon, S., Perucca, E., & Engel, J. Jr. (Eds.). (2015). *The treatment of epilepsy*, (4th ed.).

West Sussex, England: John Wiley & Sons.

Sims-Schouten, W., Riley, S.C.E., & Willig, C. (2007). Critical realism in discourse analysis: A presentation of a systemic method of analysis using women's talk of motherhood, childcare and female employment as an example. *Theory & Psychology, 17*(1), 101-124.

Siqueira, N.F., Oliveira, F.L.B.B., Siqueira, J.A., & De Souza, E.A.P. (2015). In adolescents with epilepsy, high scores of anxiety and depression are associated with occurrence of seizures in public places. *Arquivos de Neoru-Psiquiatria, 73*(3), 205-211. doi:10.1590/0004-282X20140235

Skinner, E.A., Edge, K., Altman, J., & Sherwood, H. (2003). Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. *Psychological bulletin, 129*(2), 216-269. doi:10.1037/0033-2909.129.2.216

Skyttner, L. (2006). *General systems theory: Problems, perspectives, practice.* River Edge, NJ: World Scientific.

Smith, G., Wagner, J., Andrews, J., Austin, J. Mueller, M., Carter, E., & Griesemer, K. (2014). Caregiving in pediatric epilepsy: Results of focus groups and implications for research and practice. *Epilepsy & Behavior, 43,* 34-41. doi:10.1016/j.yebeh.2014.03.002

Smith-Acuna, S. (2010). *Systems theory in action: Applications to individuals in family therapy.* Hoboken, NJ: John Wiley & Sons.

Solomon, N., & McHale, K. (2012). An overview of epilepsy in children and young people. *Nursing Children and Young People*, *24*(6), 28-35.

Spangenberg, J.J., & Lalkhen, N. (2006). Children with epilepsy and their families: Psychosocial issues. *South African Family Practice, 48*(6), 60-63. doi:10.1080/20786204.2006.10873411

Sprenkle, D. H., Olson, D., & Russell, C. S. (2014). *Circumplex model: Systemic assessment and treatment of families*. London, England: Routledge.

Staccini, L., Tomba, E., Grandi, S., & Keitner, G.I. (2015). The evaluation of family functioning by the Family Assessment Device: A systematic review of studies in adult clinical populations. *Family Process, 54*(1), 94-115. doi:10.1111/famp.12098

Steele, G.R. (2005). Critical thoughts about critical realism. *Critical Review*, *17*(1-2), 133-154, doi:10.1080/08913810508443632

Stevenson-Hinde, J.O.A.N., & Akister, J. (1995). The McMaster Model of Family Functioning: Observer and parental ratings in a nonclinical sample. *Family Process*, *34*(3), 337-347.

Stuart, J., & Jose, P.E. (2012). The influence of discrepancies between adolescent and parent ratings of family dynamics on the well-being of adolescents. *Journal of Family Psychology, 26*(6), 858-868.

Taylor, S.J., Bogdan, R., & DeVault, M. (2015). *Introduction to qualitative research methods: A guidebook and resource* (4th ed.). Hoboken, NJ: John Wiley & Sons.

Thomson, L., Fayed, N., Sedarous, F., & Ronen, G.M. (2014). Life quality and health in adolescents and emerging adults with epilepsy during the years of transition: A scoping review. *Developmental Medicine & Child Neurology, 56*(5), 421-433. doi:10.1111/dmcn.12335

Tieffenberg, J. A., Wood, E. I., Alonso, A., Tossutti, M. S., & Vicente, M. F. (2000). A randomized field trial of ACINDES: a child-centered training model for children with chronic illnesses (asthma and epilepsy). *Journal of Urban Health*, *77*(2), 280-297.

Todd, Z., Nerlich, B., McKeown, S., & Clarke, D.D. (Eds.). (2004). *Mixing methods in psychology: The integration of qualitative and quantitative methods in theory and practice*. New York, NY: Psychology Press.

Tolaymat, A., Nayak, A., Geyer, J.D., Geyer, S.K., & Carney, P.R. (2015). Diagnosis and management of childhood epilepsy. *Current Problems in Pediatric and Adolescent Health Care, 45*(1), 3-17. doi:10.1016/j.cppeds.2014.12.002

Trivette, C. M., Dunst, C.J., Deal, A.G., Hamer, A.W., & Propst, S. (1990). Assessing family strengths and family functioning style. *Topics in Early Childhood Special Education*, *10*(1), 16-35.

Vall Castello, B. (2013). *Bridging constructivism and social constructivism: A dialogical and relational approach to narrative and meaning making* (Unpublished doctoral dissertation). Universitat Ramon Llull, Barcelona, Spain.

Van Hoek, C.F. (1991). *Validering van grafiese gesinsbeelding as psigodinamiese tegniek*. (Unpublished master's thesis). Potchefstroom University, South Africa.

Veeravigrom, M., French, B.C., Thomas, R., & Sivaswamy, L. (2013). Adherence to quality measures in a pediatric epilepsy center: A pilot study. *Pediatric Neurology, 48*(4), 291-293. doi:10.1016/j.pediatrneurol.2012.12.011

Venter, C.A. (1989). Graphic family sculpting. In Mason, J. & Rubenstein, J., (Eds.) *Family therapy in South Africa today.* Congella: S.A. Institute of Marital and Family Therapy, 183-192.

Venter, C.A., (1993). Graphic family sculpting as a technique in family therapy. *Die Maatskaplikewerknavorser-Praktisyn*, 12-15.

Venter, C.A. (1994). Grafische Gezinsbeelding. *Systeemtherapie*, *4*, 214-223.

Venter, C.A. (2014). *Graphic Family Sculpting.* Class notes for Masters students in Psychology presented in class at the University of the North West, Potchefstroom, South Africa.

Venter, C.A., Du Toit, E., & Du Toit, M. (2002). Individuals' experience of individually applied Graphic Family Sculpting. *The Social Work Practitioner-Researcher, 14*(2), 44-61.

Venter, C.A., Van Rensburg, E., & Du Plessis, J.C. (1997). The impact of Graphic Family Sculpting on individuals' perception of their families of origin. *The Social Work Practitioner-Researcher, 10*(2), 134-148.

Vogt, H., Hofmann, B., & Getz, L. (2016). The new holism: P4 systems medicine and the medicalization of health and life itself. *Medicine, Health Care and Philosophy, 19*(2), 307-323.

Von Bertalanffy, L. (1972). The history and status of general systems theory. *Academy of Management Journal 15*(4), 407-426. Retrieved from http://www.jstor.org/discover/10.2307/255139?uid=3739256&uid=2&uid=4&sid=2110 1538501451

Von Bertalanffy, L. (1981). *A systems view of man.* Boulder, CO: West View Press.

Wagner, C., Kawulich, B.B., & Garner, M. (Eds.). (2012). *Doing social research: A global context.* London, England: McGraw-Hill.

Walker. M.C., & Hirsch, L.J. (2016). Emergency treatment of seizures and status epilepticus. In S.D. Shorvon, E. Perucca, & E. Engel, J. Jr. (Eds.). *The treatment of epilepsy,* (4th ed., pp. 221-243. West Sussex, England: John Wiley & Sons.

Walsh, F. (2012). *Normal Family Processes: Growing diversity and complexity*. New York, NY: Guilford Press.

Walsh, F. (2015). *Strengthening family resilience,* (3rd ed.). New York, NY: Guilford Press.

Walsh, D., & Evans, K. (2014). Critical realism: An important theoretical perspective for midwifery research. *Midwifery, 30*(1), 1-e. doi:10.1016/j.midw.2013.09.002

Wang, Y.H., Haslam, M., Yu, M., Ding, J., Lu, Q., & Pan, F. (2015). Family functioning, marital quality and social support in Chinese patients with epilepsy. *Health and Quality of Life Outcomes, 13*(1), 10. doi:10.1186/s12955-015-0208-6

Wedemeyer, N.V., & Grotevant, H.D. (1982). Mapping the family system: A technique for teaching family systems theory concepts. *Family Relations, 31*(2), 185-193.

Weiss, J.A., Robinson, S., Fung, S., Tint, A., Chalmers, P., & Lunsky, Y. (2013). Family hardiness, social support, and self-efficacy in mothers of individuals with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders, 7*(11), 1310-1317. doi:10.1016/j.rasd.2013.07.016

Wellisch, D.K. (1996). A family systems approach to coping with cancer. In R.H. Mikesell, D.D.E. Lusterman, & S.H. McDaniel (Eds.). *Integrating family therapy: Handbook of family psychology and systems theory.* Washington, DC: American Psychological Association.

Williams, N., Nefdt, W.M., & Wilmshurst, J.M. (2015). Epilepsy South Africa: Turning obstacles into true potential. *Epilepsia, 56*(2), 184-187. doi:10.1111/epi.12641

Willig, C. (1998). Social constructionism and revolutionary socialism: A contradiction in terms? In I. Parker (Ed.). *Social constructionism, discourse and realism.* London, England: Sage.

Willig, C. (2013). *Introducing qualitative research in psychology,* (3rd ed.). Berkshire, England: McGraw-Hill.

Willig, C. (2014). Interpretation and analysis. In U. Flick (Ed.). *The SAGE handbook of qualitative data analysis* (pp. 136-149). Los Angeles, CA: Sage.

Willig, C. (2016). Constructivism and 'The Real World': Can they co-exist? *QMiP Bulletin, 21.* Retrieved from http://openaccess.city.ac.uk/13576/

Wirrel, E.C., Wood, L., Hamiwka, L.D., & Sherman, E.M.S. (2008). Parenting stress in mothers of children with intractable epilepsy. *Epilepsy & Behavior, 13*(1), 169-173.

Wittink, M. N., Barg, F. K., & Gallo, J. J. (2006). Unwritten rules of talking to doctors about depression: Integrating qualitative and quantitative methods. *The Annals of Family Medicine*, *4*(4), 302-309.

Wood, B.L. (1996). A developmental biopsychosocial approach to the treatment of chronic illness in children and adolescents. In R.H. Mikesell, D.D.E. Lusterman, & S.H. McDaniel (Eds.). *Integrating family therapy: Handbook of family psychology and systems theory.* Washington, DC: American Psychological Association.

Woods, N. F., & Catanzaro, M. (1988). *Nursing research: Theory and practice* (pp. 438-439). St. Louis, MO: Mosby.

Woodson, K.D., Thakkar, S., Burbage, M., Kichler, J. & Nabors, L. (2015). Children with chronic illnesses: Factors influencing family hardiness. *Issues in Comprehensive Pediatric Nursing, 38*(1), 57-69. doi:10.3109/01460862.2014.988896

Wu, Y.P., Follansbee-Junger, K., Rausch, J., & Modi, A. (2014). Parent and family stress factors predict health-related quality in pediatric patients with new-onset epilepsy. *Epilepsia, 55*(6), 866-877. doi:10.1111/epi.12586

Zachariadis, M., Scott, S.V., & Barrett, M.I. (2013). Methodological implications of critical realism for mixed-methods research. *MIS Quarterly, 37*(3)*,* 855-879.

Zamani, G., Shiva, S., Mohammadi, M., Gharaie, J.M., & Rezaei, N. (2014). A survey of quality of life in adolescents with epilepsy in Iran. *Epilespy & Behavior, 33,* 69-72. doi:10.1016/j.yebeh.2014.02.012

Zebrack, B. J., Block, R., Hayes-Lattin, B., Embry, L., Aguilar, C., Meeske, K. A., . . . Cole, S. (2013). Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. *Cancer*, *119*(1), 201-214.

Zhang, W., & Creswell, J. (2013). The use of “mixing” procedure of mixed methods in health services research. *Medical Care, 51*(8)*,* 51-57.

Appendix A: Family Questionnaire

Questionnaire to be completed by the family

Respondent number

For Office Use Only

V0 ☐

Section A: Biographical information

1. How many members (including yourself) do you have in your family?

____

V1 ☐

2. For each person **living in your household**, please list the following information, indicating the nature of each person's role in the house (e.g. husband, wife, son, daughter, sister, grandmother, etc.)

	Name	Family role (a)	Age (b)	Gender (c)	Highest level of education of adults (d)		a	b	c	d
1						**A2.1**				
2						**A2.2**				
3						**A2.3**				
4						**A2.4**				
5						**A2.5**				
6						**A2.6**				
7						**A2.7**				

3. For each family member **not living in the home**, please list the following information, indicating the nature of each person's role in the house (e.g. husband, wife, son, daughter, sister, grandmother, etc.)

	Name	Family role (a)	Age (b)	Gender (c)	Highest level of education of adults (d)		a	b	c	d
1						**A3.1**				
2						**A3.2**				
3						**A3.3**				
4						**A3.4**				
5						**A3.5**				

4. How long has your adolescent child been diagnosed with epilepsy?

_____________ years, ____________ months

A4.1 ☐

A4.2 ☐

5. What type of epilepsy does your epileptic adolescent child have? (Please tick all applicable.)

1 Generalised seizures		A5.1	☐
Tonic clonic (grand mal) - staring, stiffening of body and jerking		A5.2	☐
Absence - blank staring for up to 3 seconds		A5.3	☐
Tonic - stiffening of muscles		A5.4	☐
Clonic – Jerky movements		A5.5	☐
Atonic – body becomes limp		A5.6	☐
Myoclonic – sudden brief jerks or twitches of arms and legs		A5.7	☐
2 Partial seizures		A5.8	☐
Simple – no loss of consciousness – twitching of thumb, arm or face		A5.9	☐
Complex – loss of awareness, but not consciousness – repetitive movements such as blinking or lip smacking		A5.10	☐

6. Please indicate if your epileptic adolescent child lives with:

Both his/her parents	
His/her mother only	
His/her father only	
Extended family	
Other (please specify)	

A6 ☐

8. Please indicate the marital status of the head of the household:

Single (never been married)	
Married	
Divorced	
Separated	
Widowed	
Living together, but not married	

A8 ☐

9. Please indicate if the father :

Has his own business	
Works for one employer	
Works for more than one employer	
Is retired	
Is unemployed	
Other (please specify)	

A9 ☐

10. Please indicate if the mother :

Has her own business	
Works for one employer	
Works for more than one employer	
Is retired	
Is unemployed	
Other (please specify)	

A10 ☐

11. If the father is employed, does he work full or half day?

Full-day	
Half-day	

A11 ☐

12. If the mother is employed, does she work full or half day?

Full-day	
Half-day	

A12 ☐

13. Please indicate to which ethnic group you belong:

African	
Coloured	
Indian	
White	
Other (please specify)	

A13 ☐

14. Please indicate the total household income per month

R0 – R9 999	
R10 000 – R19 999	
R20 000 – R29 999	
R30 000 – R39 999	
R40 000 -- R49 999	
R50 000 – R59 999	
R60 000 – R69 999	
R70 000 – R79 999	
R80 000 – R89 000	
R90 000 – R99 000	
R100 000 and more	

A14 ☐

Section B: Family Satisfaction Scale (FSS)

Please indicate to which extent the following applies to you by marking a cross (x) over the number you choose.

	How satisfied are you :	Dissatisfied	Somewhat dissatisfied	Generally satisfied	Very satisfied	Extremely satisfied		
1	With how close you feel to the rest of your family?	1	2	3	4	5	**B1**	
2	With your ability to say what you want in your family?	1	2	3	4	5	**B2**	
3	With your family's ability to try new things?	1	2	3	4	5	**B3**	
4	With how often parents make decisions in your family?	1	2	3	4	5	**B4**	
5	With how much mother and father argue with each other?	1	2	3	4	5	**B5**	
6	With how fair the criticism is in your family?	1	2	3	4	5	**B6**	
7	With the amount of time you spend with your family?	1	2	3	4	5	**B7**	
8	With the way you talk together to solve family problems?	1	2	3	4	5	**B8**	
9	With your freedom to be alone when you want to?	1	2	3	4	5	**B9**	
10	With how strictly you stay with who does what chores in your family?	1	2	3	4	5	**B10**	
11	With your family's acceptance of your friends?	1	2	3	4	5	**B11**	
12	With how clear is it what your family expects of you?	1	2	3	4	5	**B12**	
13	With how often you make decisions as a family, rather than individually?	1	2	3	4	5	**B13**	
14	With the number of fun things your family does together?	1	2	3	4	5	**B14**	

Section C: Family Functioning Style Scale (FFS)

Please indicate to which extent the following is true for your family by marking a cross (x) over the number you choose.

	To what extent is each of the following statements like your family:	Not at all like my family	A little like my family	Sometimes like my family	Generally like my family	Almost always like my family		
1	It is worth making personal sacrifices if it benefits our family	0	1	2	3	4	**C1**	
2	We generally agree about how family members are expected to behave	0	1	2	3	4	**C2**	
3	We believe that something good comes out of the worst situations	0	1	2	3	4	**C3**	
4	We take pride in even the smallest accomplishments of family members	0	1	2	3	4	**C4**	
5	We are able to share our concerns and feelings in productive ways	0	1	2	3	4	**C5**	
6	No matter how difficult things get, our family sticks together	0	1	2	3	4	**C6**	
7	We generally ask for help from persons outside our family if we cannot do things ourselves	0	1	2	3	4	**C7**	
8	We generally agree about the things that are important to our family	0	1	2	3	4	**C8**	
9	In our family we are always willing to “pitch in” and help one another	0	1	2	3	4	**C9**	
10	If something beyond our control is constantly upsetting to our family, we find things to do that keep our minds off our worries	0	1	2	3	4	**C10**	
11	No matter what happens in our family, we try to look “at the bright side of things”	0	1	2	3	4	**C11**	
12	Even in our busy schedules, we find time to be together	0	1	2	3	4	**C12**	

Section C: Family Functioning Style Scale (FFS) Continued

	To what extent is each of the following statements like your family:	Not at all like my family	A little like my family	Sometimes like my family	Generally like my family	Almost always like my family		
13	Everyone in our family understands the rules about acceptable ways to act	0	1	2	3	4	C13	
14	Friends and relatives are always willing to help whenever we have a problem or crisis	0	1	2	3	4	C14	
15	When we have a problem or concern, we are able to make decisions about what to do	0	1	2	3	4	C15	
16	We enjoy time together even if it is just doing household chores	0	1	2	3	4	C16	
17	If we have a problem or concern that seems overwhelming, we try to forget it for a while	0	1	2	3	4	C17	
18	Whenever we have disagreements, family members listen to “both sides of the story”	0	1	2	3	4	C18	
19	In our family, we make time to get things done that we all agree are important	0	1	2	3	4	C19	
20	In our family, we can depend upon the support of one another whenever something goes wrong	0	1	2	3	4	C20	
21	We generally talk about the different ways we deal with problems or concerns	0	1	2	3	4	C21	
22	In our family, our relationships will outlast our material possessions	0	1	2	3	4	C22	
23	Decisions like moving or changing jobs are based upon what is best for all family members	0	1	2	3	4	C23	
24	We can depend upon one another to help out when something unexpected comes up	0	1	2	3	4	C24	
25	In our family, we try not to take one another for granted	0	1	2	3	4	C25	
26	We try to solve our problems first before asking others to help	0	1	2	3	4	C26	

Section D: Family Hardiness Index (FHI)

Please read each statement below and decide to what degree each describes your family by marking a cross (x) over the number you choose.

	In our family :	False	Mostly false	Mostly true	True		
1	Trouble results from mistakes we make	1	2	3	4	**D1**	
2	It is not wise to plan ahead and hope because things do not turn out like that anyway	1	2	3	4	**D2**	
3	Our work and efforts are not appreciated no matter how hard we try and work	1	2	3	4	**D3**	
4	In the long run the bad things that happen to us are balanced by the good things that happen	1	2	3	4	**D4**	
5	We have a sense of being strong even when facing big problems	1	2	3	4	**D5**	
6	Many times we feel that we can trust that even in difficult times things will work out	1	2	3	4	**D6**	
7	While we don't always agree, we can count on each other to stand by us in times of need	1	2	3	4	**D7**	
8	We do not feel we can survive if another problem hits us	1	2	3	4	**D8**	
9	We believe things will work for the better if we work together as a family	1	2	3	4	**D9**	
10	Life seems dull and meaningless	1	2	3	4	**D10**	
11	We strive together and help each other no matter what	1	2	3	4	**D11**	
12	When our family plans activities we try new and exciting things	1	2	3	4	**D12**	
13	We listen to each other's problems, hurts and fears	1	2	3	4	**D13**	
14	We tend to do the same thing over and over, it's boring	1	2	3	4	**D14**	
15	We seem to encourage each other to try new things and experiences	1	2	3	4	**D15**	

Section D: Family Hardiness Index (FHI) Continued

	In our family :	False	Mostly false	Mostly true	True		
16	It is better to stay at home than to go out and do things with others	1	2	3	4	D16	
17	Being active and learning new things are encouraged	1	2	3	4	D17	
18	We work together to solve problems	1	2	3	4	D18	
19	Most of the unhappy things that happen are due to bad luck	1	2	3	4	D19	
20	We realise our lives are controlled by accidents and luck	1	2	3	4	D20	

Section E: Family Assessment Device (FAD)

Read each statement carefully and decide how well it describes your family by marking a cross (x) over the number you choose.

		Strongly agree	Agree	Disagree	Strongly disagree		
1	Planning family activities is difficult because we misunderstand each other	1	2	3	4	E1	
2	We resolve most everyday problems around the house	1	2	3	4	E2	
3	When someone is upset the others know why	1	2	3	4	E3	
4	When you ask someone to do something, you have to check that they did it	1	2	3	4	E4	
5	If someone is in trouble, the others become too involved	1	2	3	4	E5	
6	In times of crisis we can turn to each other for support	1	2	3	4	E6	
7	We don't know what to do when an emergency comes up	1	2	3	4	E7	
8	We sometimes run out of things that we need	1	2	3	4	E8	
9	We are reluctant to show our affection for each other	1	2	3	4	E9	

Section E: Family Assessment Device (FAD) Continued

		Strongly agree	Agree	Disagree	Strongly disagree		
10	We make sure members meet their family responsibilities	1	2	3	4	**E10**	
11	We cannot talk to each other about the sadness we feel	1	2	3	4	**E11**	
12	We usually act on our decisions regarding problems	1	2	3	4	**E12**	
13	You only get the interest of others when something is important to them	1	2	3	4	**E13**	
14	You can't tell how a person is feeling from what they are saying	1	2	3	4	**E14**	
15	Family tasks don't get spread around enough	1	2	3	4	**E15**	
16	Individuals are accepted for what they are	1	2	3	4	**E16**	
17	You can easily get away with breaking the rules	1	2	3	4	**E17**	
18	People come right out and say things instead of hinting at them	1	2	3	4	**E18**	
19	Some of us just don't respond emotionally	1	2	3	4	**E19**	
20	We know what to do in an emergency	1	2	3	4	**E20**	
21	We avoid discussing our fears and concerns	1	2	3	4	**E21**	
22	It is difficult to talk to each other about tender feelings	1	2	3	4	**E22**	
23	We have trouble meeting our financial obligations	1	2	3	4	**E23**	
24	After our family tries to solve a problem, we usually discuss whether it worked or not	1	2	3	4	**E24**	
25	We are too self-centered	1	2	3	4	**E25**	
26	We can express feelings to each other	1	2	3	4	**E26**	
27	We have no clear expectations about toilet habits	1	2	3	4	**E27**	
28	We do not show our love for each other	1	2	3	4	**E28**	
29	We talk to people directly rather than through go-betweens	1	2	3	4	**E29**	
30	Each of us has particular duties and responsibilities	1	2	3	4	**E30**	
31	There are lots of bad feelings in the family	1	2	3	4	**E31**	

Section E: Family Assessment Device (FAD) Continued

		Strongly agree	Agree	Disagree	Strongly disagree		
32	We have rules about hitting people	1	2	3	4	E32	
33	We get involved with each other only when something interests us	1	2	3	4	E33	
34	There is little time to explore personal interests	1	2	3	4	E34	
35	We often don't say what we mean	1	2	3	4	E35	
36	We feel accepted for what we are	1	2	3	4	E36	
37	We show interest in each other when we can get something out of it personally	1	2	3	4	E37	
38	We resolve most emotional upsets that come up	1	2	3	4	E38	
39	Tenderness takes second place to other things in our family	1	2	3	4	E39	
40	We discuss who are responsible for household jobs	1	2	3	4	E40	
41	Making decisions is a problem for our family	1	2	3	4	E41	
42	Our family shows interest in each other only when they can get something out of it	1	2	3	4	E42	
43	We are frank (direct, straightforward) with each other	1	2	3	4	E43	
44	We don't hold to any rules or standards	1	2	3	4	E44	
45	If people are asked to do something, they need reminding	1	2	3	4	E45	
46	We are able to make decisions about how to solve problems	1	2	3	4	E46	
47	If the rules are broken, we don't know what to expect	1	2	3	4	E47	
48	Anything goes in our family	1	2	3	4	E48	
49	We express tenderness	1	2	3	4	E49	
50	We confront problems involving feelings	1	2	3	4	E50	
51	We don't get along well together	1	2	3	4	E51	
52	We don't talk to each other when we are angry	1	2	3	4	E52	
53	We are generally dissatisfied with the family duties assigned to us	1	2	3	4	E53	

Section E: Family Assessment Device (FAD) Continued

		Strongly agree	Agree	Disagree	Strongly disagree		
54	Even though we mean well, we intrude too much into each other's lives	1	2	3	4	**E54**	
55	There are rules in our family about dangerous situations	1	2	3	4	**E55**	
56	We confide in each other	1	2	3	4	**E56**	
57	We cry openly	1	2	3	4	**E57**	
58	We don't have basic reasonable transport	1	2	3	4	**E58**	
59	When we don't like what someone has done, we tell them	1	2	3	4	**E59**	
60	We try to think of different ways to solve problems	1	2	3	4	**E60**	

Appendix B: Patient Questionnaire

For Office Use Only

PATIENT QUESTIONNAIRE

Respondent number

V0 ☐

Section A: Biographical information

1. How old are you? ______ years

A1 ☐

2. What is your gender?

Male	1	Female	2

A2 ☐

3. Please indicate to which ethnic group you belong:

African	1
Coloured	2
Indian	3
White	4
Other(specify)	

A3 ☐

4. How long have you been diagnosed with epilepsy?

_____________ years, or ____________ months

A4.1 ☐

A4.2 ☐

5. Please indicate if:

You live with both your parents	
You live with your mother only	
You live with your father only	
You live with extended family	
Other (please specify)	

A5 ☐

6. Where do you usually stay after school?

At an after school care centre	
At home with a parent	
At home with a care-giver such as an au pair or granny	
At home without adult supervision	
Other (please specify)	

A6 ☐

7. Do you participate in any of the following extra-mural activities? (Please tick all applicable.)

Sport (e.g. rugby, soccer, tennis, netball, hockey)		**A7.1**	
Cultural activities (e.g. choir, music lessons, modern dancing, debate)		**A7.2**	
Religious activities (e.g. church, Bible study, groups)		**A7.3**	
Other (please specify)		**A7.4**	

Section B: Family Satisfaction Scale (FSS)

Please indicate to which extent the following applies to you by marking a cross (x) over the number you choose.

	How satisfied are you :	Dissatisfied	Somewhat dissatisfied	Generally satisfied	Very satisfied	Extremely satisfied		
1	With how close you feel to the rest of your family?	1	2	3	4	5	**B1**	
2	With your ability to say what you want in your family?	1	2	3	4	5	**B2**	
3	With your family's ability to try new things?	1	2	3	4	5	**B3**	
4	With how often parents make decisions in your family?	1	2	3	4	5	**B4**	
5	With how much mother & father argue with each other?	1	2	3	4	5	**B5**	
6	With how fair the criticism is in your family?	1	2	3	4	5	**B6**	
7	With the amount of time you spend with your family?	1	2	3	4	5	**B7**	
8	With the way you talk together to solve family problems?	1	2	3	4	5	**B8**	
9	With your freedom to be alone when you want to?	1	2	3	4	5	**B9**	
10	With how strictly you stay with who does what chores in your family?	1	2	3	4	5	**B10**	
11	With your family's acceptance of your friends?	1	2	3	4	5	**B11**	
12	With how clear is it what your family expects of you?	1	2	3	4	5	**B12**	
13	With how often you make decisions as a family, rather than individually?	1	2	3	4	5	**B13**	
14	With the number of fun things your family does together?	1	2	3	4	5	**B14**	

Section C: Family Functioning Style Scale (FFS)

Please indicate to which extent the following is true for your family by marking a cross (x) over the number you choose.

	To what extent is each of the following statements like your family:	Not at all like my family	A little like my family	Sometimes like my family	Generally like my family	Almost always like my family		
1	It is worth making personal sacrifices if it benefits our family	0	1	2	3	4	**C1**	
2	We generally agree about how family members are expected to behave	0	1	2	3	4	**C2**	
3	We believe that something good comes out of the worst situations	0	1	2	3	4	**C3**	
4	We take pride in even the smallest accomplishments of family members	0	1	2	3	4	**C4**	
5	We are able to share our concerns and feelings in productive ways	0	1	2	3	4	**C5**	
6	No matter how difficult things get, our family sticks together	0	1	2	3	4	**C6**	
7	We generally ask for help from persons outside our family if we cannot do things ourselves	0	1	2	3	4	**C7**	
8	We generally agree about the things that are important to our family	0	1	2	3	4	**C8**	
9	In our family we are always willing to “pitch in” and help one another	0	1	2	3	4	**C9**	
10	If something beyond our control is constantly upsetting to our family, we find things to do that keep our minds off our worries	0	1	2	3	4	**C10**	
11	No matter what happens in our family, we try to look “at the bright side of things”	0	1	2	3	4	**C11**	
12	Even in our busy schedules, we find time to be together	0	1	2	3	4	**C12**	

Section C: Family Functioning Style Scale (FFS) Continued

	To what extent is each of the following statements like your family:	Not at all like my family	A little like my family	Sometimes like my family	Generally like my family	Almost always like my family		
13	Everyone in our family understands the rules about acceptable ways to act	0	1	2	3	4	**C13**	
14	Friends and relatives are always willing to help whenever we have a problem or crisis	0	1	2	3	4	**C14**	
15	When we have a problem or concern, we are able to make decisions about what to do	0	1	2	3	4	**C15**	
16	We enjoy time together even if it is just doing household chores	0	1	2	3	4	**C16**	
17	If we have a problem or concern that seems overwhelming, we try to forget it for a while	0	1	2	3	4	**C17**	
18	Whenever we have disagreements, family members listen to "both sides of the story"	0	1	2	3	4	**C18**	
19	In our family, we make time to get things done that we all agree are important	0	1	2	3	4	**C19**	
20	In our family, we can depend upon the support of one another whenever something goes wrong	0	1	2	3	4	**C20**	
21	We generally talk about the different ways we deal with problems or concerns	0	1	2	3	4	**C21**	
22	In our family, our relationships will outlast our material possessions	0	1	2	3	4	**C22**	
23	Decisions like moving or changing jobs are based upon what is best for all family members	0	1	2	3	4	**C23**	
24	We can depend upon one another to help out when something unexpected comes up	0	1	2	3	4	**C24**	
25	In our family, we try not to take one another for granted	0	1	2	3	4	**C25**	
26	We try to solve our problems first before asking others to help	0	1	2	3	4	**C26**	

Section D: Family Hardiness Index (FHI)

Please read each statement below and decide to what degree each describes your family by marking a cross (x) over the number you choose.

	In our family :	False	Mostly false	Mostly true	True		
1	Trouble results from mistakes we make	1	2	3	4	**D1**	
2	It is not wise to plan ahead and hope because things do not turn out like that anyway	1	2	3	4	**D2**	
3	Our work and efforts are not appreciated no matter how hard we try and work	1	2	3	4	**D3**	
4	In the long run the bad things that happen to us are balanced by the good things that happen.	1	2	3	4	**D4**	
5	We have a sense of being strong even when facing big problems	1	2	3	4	**D5**	
6	Many times we feel that we can trust that even in difficult times things will work out	1	2	3	4	**D6**	
7	While we don't always agree, we can count on each other to stand by us in times of need	1	2	3	4	**D7**	
8	We do not feel we can survive if another problem hits us	1	2	3	4	**D8**	
9	We believe things will work for the better if we work together as a family	1	2	3	4	**D9**	
10	Life seems dull and meaningless	1	2	3	4	**D10**	
11	We strive together and help each other no matter what	1	2	3	4	**D11**	
12	When our family plans activities we try new and exciting things	1	2	3	4	**D12**	
13	We listen to each other's problems, hurts and fears	1	2	3	4	**D13**	
14	We tend to do the same thing over and over, it's boring	1	2	3	4	**D14**	
15	We seem to encourage each other to try new things and experiences					**D15**	

Section D: Family Hardiness Index (FHI) Continued

	In our family :	False	Mostly false	Mostly true	True		
16	It is better to stay at home than to go out and do things with others	1	2	3	4	**D16**	
17	Being active and learning new things are encouraged	1	2	3	4	**D17**	
18	We work together to solve problems	1	2	3	4	**D18**	
19	Most of the unhappy things that happen are due to bad luck	1	2	3	4	**D19**	
20	We realise our lives are controlled by accidents and luck	1	2	3	4	**D20**	

Section E: Family Assessment Device (FAD)

Read each statement carefully and decide how well it describes your family by marking a cross (x) over the number you choose.

		Strongly agree	Agree	Disagree	Strongly disagree		
1	Planning family activities is difficult because we misunderstand each other	1	2	3	4	**E1**	
2	We resolve most everyday problems around the house	1	2	3	4	**E2**	
3	When someone is upset the others know why	1	2	3	4	**E3**	
4	When you ask someone to do something, you have to check that they did it	1	2	3	4	**E4**	
5	If someone is in trouble, the others become too involved	1	2	3	4	**E5**	
6	In times of crisis we can turn to each other for support	1	2	3	4	**E6**	
7	We don't know what to do when an emergency comes up	1	2	3	4	**E7**	
8	We sometimes run out of things that we need	1	2	3	4	**E8**	
9	We are reluctant to show our affection for each other	1	2	3	4	**E9**	

Section E: Family Assessment Device (FAD) Continued

		Strongly agree	Agree	Disagree	Strongly disagree		
10	We make sure members meet their family responsibilities	1	2	3	4	**E10**	
11	We cannot talk to each other about the sadness we feel	1	2	3	4	**E11**	
12	We usually act on our decisions regarding problems	1	2	3	4	**E12**	
13	You only get the interest of others when something is important to them	1	2	3	4	**E13**	
14	You can't tell how a person is feeling from what they are saying	1	2	3	4	**E14**	
15	Family tasks don't get spread around enough	1	2	3	4	**E15**	
16	Individuals are accepted for what they are	1	2	3	4	**E16**	
17	You can easily get away with breaking the rules	1	2	3	4	**E17**	
18	People come right out and say things instead of hinting at them	1	2	3	4	**E18**	
19	Some of us just don't respond emotionally	1	2	3	4	**E19**	
20	We know what to do in an emergency	1	2	3	4	**E20**	
21	We avoid discussing our fears and concerns	1	2	3	4	**E21**	
22	It is difficult to talk to each other about tender feelings	1	2	3	4	**E22**	
23	We have trouble meeting our financial obligations	1	2	3	4	**E23**	
24	After our family tries to solve a problem, we usually discuss whether it worked or not	1	2	3	4	**E24**	
25	We are too self-centered	1	2	3	4	**E25**	
26	We can express feelings to each other	1	2	3	4	**E26**	
27	We have no clear expectations about toilet habits	1	2	3	4	**E27**	
28	We do not show our love for each other	1	2	3	4	**E28**	
29	We talk to people directly rather than through go-betweens	1	2	3	4	**E29**	
30	Each of us has particular duties and responsibilities	1	2	3	4	**E30**	
31	There are lots of bad feelings in the family	1	2	3	4	**E31**	

Section E: Family Assessment Device (FAD) Continued

		Strongly agree	Agree	Disagree	Strongly disagree		
32	We have rules about hitting people	1	2	3	4	E32	
33	We get involved with each other only when something interests us	1	2	3	4	E33	
34	There is little time to explore personal interests	1	2	3	4	E34	
35	We often don't say what we mean	1	2	3	4	E35	
36	We feel accepted for what we are	1	2	3	4	E36	
37	We show interest in each other when we can get something out of it personally	1	2	3	4	E37	
38	We resolve most emotional upsets that come up	1	2	3	4	E38	
39	Tenderness takes second place to other things in our family	1	2	3	4	E39	
40	We discuss who are responsible for household jobs	1	2	3	4	E40	
41	Making decisions is a problem for our family	1	2	3	4	E41	
42	Our family shows interest in each other only when they can get something out of it	1	2	3	4	E42	
43	We are frank (direct, straightforward) with each other	1	2	3	4	E43	
44	We don't hold to any rules or standards	1	2	3	4	E44	
45	If people are asked to do something, they need reminding	1	2	3	4	E45	
46	We are able to make decisions about how to solve problems	1	2	3	4	E46	
47	If the rules are broken, we don't know what to expect	1	2	3	4	E47	
48	Anything goes in our family	1	2	3	4	E48	
49	We express tenderness	1	2	3	4	E49	
50	We confront problems involving feelings	1	2	3	4	E50	
51	We don't get along well together	1	2	3	4	E51	
52	We don't talk to each other when we are angry	1	2	3	4	E52	
53	We are generally dissatisfied with the family duties assigned to us	1	2	3	4	E53	

Section E: Family Assessment Device (FAD) Continued

		Strongly agree	Agree	Disagree	Strongly disagree		
54	Even though we mean well, we intrude too much into each other's lives	1	2	3	4	**E54**	
55	There are rules in our family about dangerous situations	1	2	3	4	**E55**	
56	We confide in each other	1	2	3	4	**E56**	
57	We cry openly	1	2	3	4	**E57**	
58	We don't have basic reasonable transport	1	2	3	4	**E58**	
59	When we don't like what someone has done, we tell them	1	2	3	4	**E59**	
60	We try to think of different ways to solve problems	1	2	3	4	**E60**	

Appendix C: Information Leaflet

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

FACULTY OF HUMANITIES
DEPARTMENT OF PSYCHOLOGY

PARTICIPATION IN RESEARCH ON ADOLESCENT EPILEPSY AND FAMILY PROCESSES

Researchers' detail:

Karlien Erasmus (Counselling Psychologist) - karlien@erasmustherapy.com / 012-362-7380

Information leaflet to participate in the research

Dear participant

I am a Counselling Psychologist, currently completing a PhD at the University of Pretoria under the promotion of Prof Terri Bakker. This introductory letter is intended to identify those participants who are willing to participate in the research.

1. **Title of the study**

Family processes and coping strategies of families of adolescents diagnosed with epilepsy.

2. **Purpose of the study**

The general purpose of the study is to explore the family process and coping strategies of families of adolescent patients who have been diagnosed with epilepsy. It is believed that this research could contribute to current knowledge in the field of psychology and may be used proactively. Results may assist medical specialists to treat patients more effectively taking in to consideration both the emotional aspects as well as the physiological or medical aspects when treating an adolescent patient with epilepsy.

3. **Procedures**

The adolescent patient (age 13 to 18 years) as well as his or her family members (parents or guardian and siblings or any other family member living with the patient and seen by the patient as part of his or her core family) will be invited to participate in the research. Gathering of data will take place on the same day as when you will come to see your neurologist for a follow-up appointment. Participation in the research will be as follows, and will all be part of a once off appointment with the researcher, including your family: .1 There will be an interview with you and your family – duration of ± 1 hour to 1 hour 30 minutes. Siblings from the age of 5 years old can participate in the interview. This interview will be recorded on video or DVD. 3.2 Then it will take another 30 minutes to complete a number of questionnaires.

4. **Risks and discomforts**

No physical or emotional risks are foreseen but if at any time, you feel that sensitive material is touched upon, or if any discomfort arises, counseling or therapy by an independent therapist will be available.

5. **Benefits**

Benefits might include becoming aware of family processes and to understand and make sense of one's family's' emotional experiences of family matters. By becoming aware of the above mentioned might assist you and your family to manage the diagnosis of epilepsy on an emotional level. There will be no financial gain in participating in the research.

6. **Participants' rights**

Participation is voluntary and you may withdraw from participation in the study at any time and without negative consequences. All records and data will be destroyed if you choose to withdraw.

7. **Confidentiality**

All information will be treated as confidential and anonymity will be assured by not including any identifiable detail and by using numbers when referring to the participants and not names. The data will be destroyed should you withdraw from the research. The persons that will have access to the research data will be: The researcher, the researchers' supervisor of the University of Pretoria, the co-coder of the data, people part of the statistical analysis and the treating specialists.

8. **Right of access to researcher**

You can make contact with me at any time during the research process (contact detail on this letter) should any doubt arise and should you seek clarity on any issue.

9. **Further research**

Data collected for research purposes will be stored at the University of Pretoria for 15 years. You will be asked to give consent that data can be used for further research.

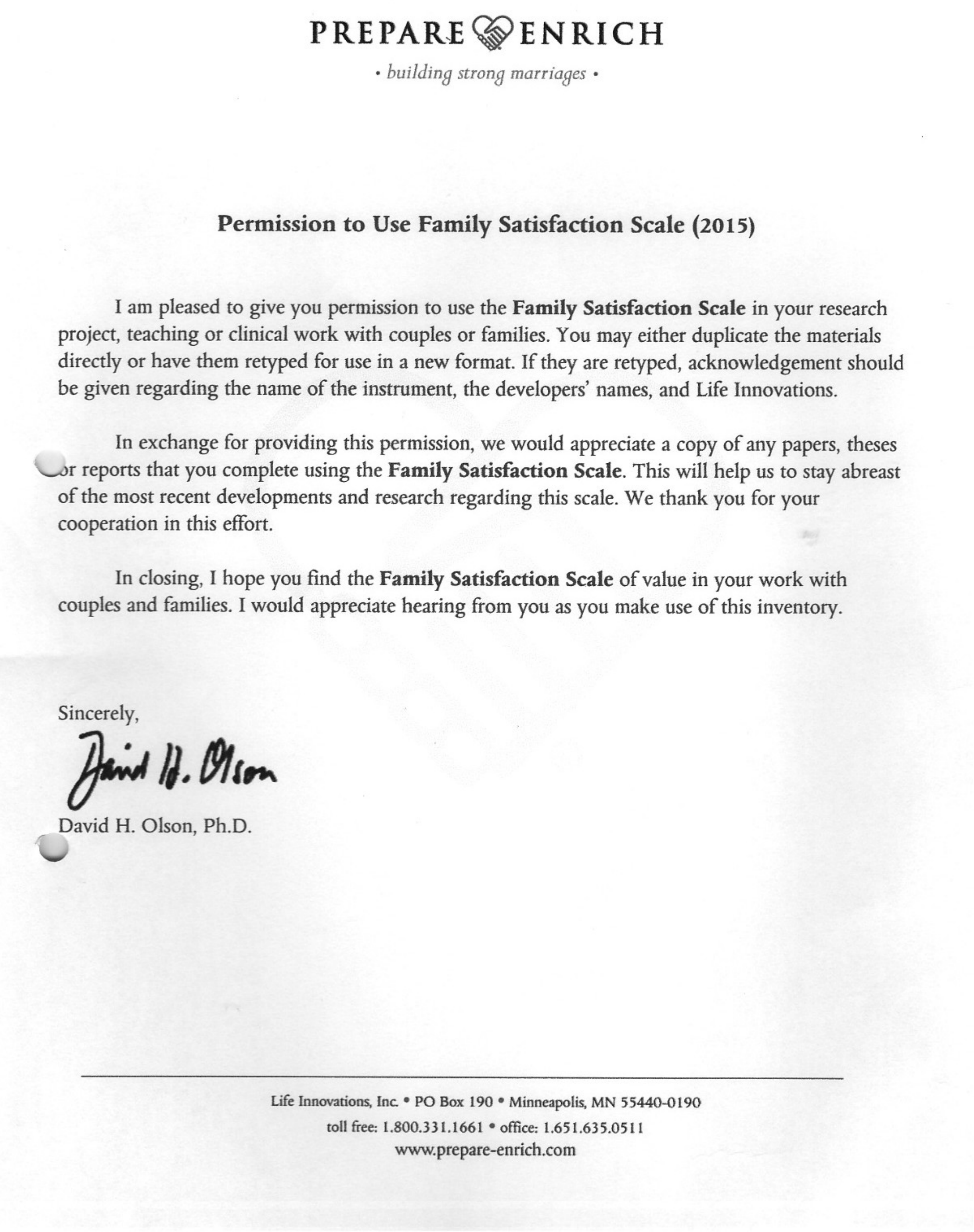
If you are willing to participate, please contact me via contact details given above.

Your interest is highly appreciated. Please contact me should you have any questions regarding the study. Thank you.

Yours,

Karlien Erasmus

Appendix D: Permission to use FSS (Prepare-Enrich)



PREPARE ENRICH
• building strong marriages •

Permission to Use Family Satisfaction Scale (2015)

I am pleased to give you permission to use the **Family Satisfaction Scale** in your research project, teaching or clinical work with couples or families. You may either duplicate the materials directly or have them retyped for use in a new format. If they are retyped, acknowledgement should be given regarding the name of the instrument, the developers' names, and Life Innovations.

In exchange for providing this permission, we would appreciate a copy of any papers, theses or reports that you complete using the **Family Satisfaction Scale**. This will help us to stay abreast of the most recent developments and research regarding this scale. We thank you for your cooperation in this effort.

In closing, I hope you find the **Family Satisfaction Scale** of value in your work with couples and families. I would appreciate hearing from you as you make use of this inventory.

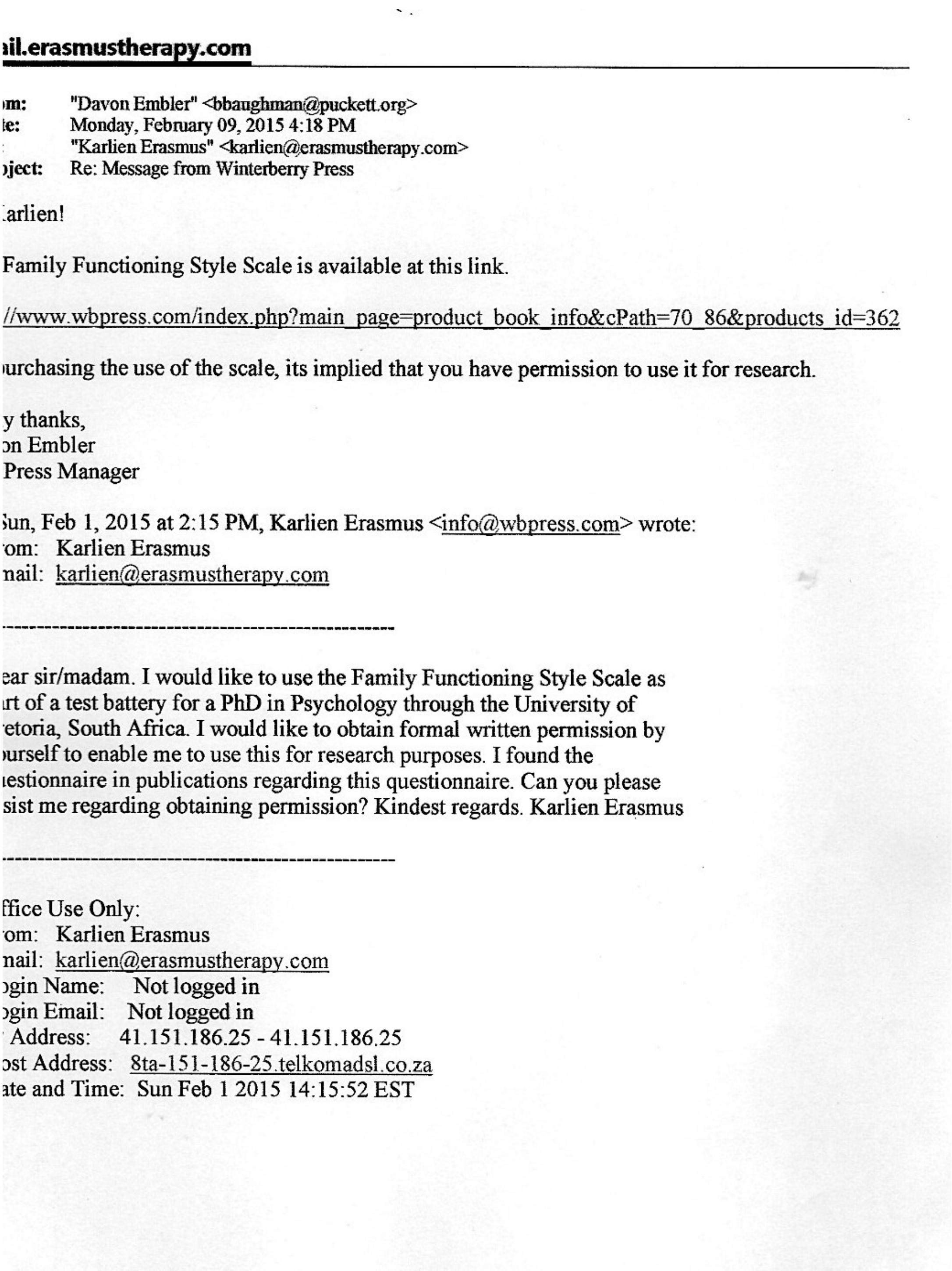
Sincerely,

David H. Olson

David H. Olson, Ph.D.

Life Innovations, Inc. • PO Box 190 • Minneapolis, MN 55440-0190
toll free: 1.800.331.1661 • office: 1.651.635.0511
www.prepare-enrich.com

Appendix E: Permission to use FFS (Winterberry Press)



ıil.erasmustherapy.com

ım: "Davon Embler" <bbaughman@puckett.org>
ıe: Monday, February 09, 2015 4:18 PM
"Karlien Erasmus" <karlien@erasmustherapy.com>
ɔject: Re: Message from Winterberry Press

.arlien!

Family Functioning Style Scale is available at this link.

//www.wbpress.com/index.php?main_page=product_book_info&cPath=70_86&products_id=362

ɹurchasing the use of the scale, its implied that you have permission to use it for research.

y thanks,
ɔn Embler
Press Manager

ǃun, Feb 1, 2015 at 2:15 PM, Karlien Erasmus <info@wbpress.com> wrote:
ʼom: Karlien Erasmus
nail: karlien@erasmustherapy.com

----

ear sir/madam. I would like to use the Family Functioning Style Scale as ırt of a test battery for a PhD in Psychology through the University of ʼetoria, South Africa. I would like to obtain formal written permission by ɔurself to enable me to use this for research purposes. I found the ıestionnaire in publications regarding this questionnaire. Can you please sist me regarding obtaining permission? Kindest regards. Karlien Erasmus

----

ffice Use Only:
ʼom: Karlien Erasmus
nail: karlien@erasmustherapy.com
ɔgin Name: Not logged in
ɔgin Email: Not logged in
Address: 41.151.186.25 - 41.151.186.25
ɔst Address: 8ta-151-186-25.telkomadsl.co.za
ate and Time: Sun Feb 1 2015 14:15:52 EST

Appendix F: Interview Schedule

Interview schedule

The interview held with the family will be facilitated by the researcher. It will include the adolescent patient and his or her family members after they have attended a follow-up appointment at the neurologist. The interview will last approximately one hour. The aim will be to assess the processes of the family 'live'.

At the start of the interview, the participants will be informed of the topic: "Talk about your experience of epilepsy in your family."

The researcher will explore family processes while focusing on the wellbeing and coping strategies of the family. Realities will be co-constructed with family members.

The following procedures will be followed during the interviews (Venter, Du Toit, & Du Toit, 2002):

- At the onset of the interview, participants will be put at ease and rapport with them established.
- It will be clearly communicated to the participants what information is needed, namely, to talk about their experiences of epilepsy in their families. Furthermore, the researcher will explain why it is necessary and how the interview is going to be conducted. This will be based on Patton's (1987) recommendations.
- Consent to record interviews on video or DVD and to make notes, will be obtained from every participant. However, the researcher will first explain why this is necessary.
- It will be an unstructured interview; based on the participants' answers, the researcher may ask further questions.
- An open-ended question in relation to the participants' experience of epilepsy in their families will be put to them. During the interview, the researcher will attempt to enter each participant's world and understand their perspective. This will be carried out by asking a number of follow-up questions in order to obtain a comprehensive picture of the participants' experience of epilepsy in their families. Throughout the process, the researcher will try to keep Anderson and Goolishian's (1992) guidelines in mind by

creating the opportunity for participants to express themselves fully. Questions will be directed to them in such a way so as to allow them the freedom to say that they do not know instead of leading them to perceive that specific answers were demanded of them.

- Examples of follow-up questions may include the following: “How are things different since the diagnoses?”; “How do you feel about it?”; “How does it make your life different?”; “Does it have any effect on who the family is?”; and “Does it have any effect on how the family operates?”
- The researcher will also examine who the members in the system are, what the characteristic patterns of interaction in this system are, and what rules and roles form the boundaries of the system and distinguish it as separate from other systems.
- After the participants are satisfied that they have shared a comprehensive picture of their experience, the researcher will make sure that there were no uncertainties.
- At the end of the interview, the participants will be reminded that they can further discuss their GFS with the researcher or appointed psychologist should they wish to do so.

References

Anderson, H. & Goolishian, H.A. (1988). Human systems as linguistic systems: Preliminary and evolving ideas about the implications for clinical theory. *Family Process, 27*(4), 371-393.

Patton, M.Q. (1987). *How to use qualitative methods in evaluation.* California, USA: Sage.

Venter, C.A., Du Toit, E., & Du Toit, M. (2002). Individuals’ experience of individually applied Graphic Family Sculpting. *The Social Work Practitioner Researcher, 14*(2), 44-61.

Appendix G: Instructions for Administering GFS

A summary from the article: Venter, C.A. (1993). Graphic family sculpting as a technique in family therapy. *The Social Work Practitioner-Researcher, 6*(2), 12-15.

GFS can be administered to an individual family member or to all the members of the family in a conjoint session. The person(s) is supplied with a clean sheet of A4 paper, HB pencil and an eraser. The following instructions are given:

- You should draw your family (or your family of origin or your future family) on one side of the paper. Draw your family by representing each member by means of a circle. You may draw the circle as big as you may like and may use as much space on the paper s you wish. Peoples' sketches usually differ greatly. In each circle, or write next to it, write the name and age of the relevant family member. It is important to be quiet while doing the drawing. As soon as you have finished you should wait quietly for further instructions.
- Number the circles in the order in which they were drawn.
- On the back of the paper, next to No. 1, write down whether you have discovered anything new about your family, and if so, what you discovered.
- Next to the circle write whether the person represented is sitting, lying, or standing. If you wish, you can describe the positions more fully, for example, sitting or lying comfortable.
- On the back of the paper, next to No. 2, write down whether you have discovered anything new about your family. What?
- Indicate the direction in which each person is looking. Do this by drawing an arrow pointing in the direction the relevant family member is looking. Each person can only look in one direction and although this may be difficult, you must try to choose one direction for each member. If you find this difficult, secondary directions may also be given by using dotted lines. If, according to you, it is an absolute must, one person can be looking at everybody. Then only draw one arrow with a caption "everybody." A person can even be looking away from the family members.
- On the back of the paper, next to No. 3, write down whether you have discovered anything new about your family. What?

- Allocate a name to each member of the family. Choose a name that you think represents the way the family has labeled and typified that person, for example, the quiet, the cheeky or the clever one.
- Write down the name chosen next to each circle and indicate it with a (N). IF it is impossible to decide on a name for the person, put a question mark next to the relevant circle (S).
- On the back of the paper, next to No. 4, write down whether you have discovered anything new about your family. What?
- Allocate a particular emotion to each member of the family.
- Write down the emotion chosen next to each circle and indicate it with an (E). IF it is impossible to allocate an emotion, put a question mark next to the relevant circle(s).
- On the back of the paper, next to No. 5, write down whether you have discovered anything new about your family. What?
- Finally, answer these questions on the back of your paper: Next to No. 6, write down whether you found it easy to follow the instructions. Yes or no? Next to No. 7, write down whether you have learnt anything in the process. Yes or no? Next to No. 8, write down whether you became emotional during the process. Yes or no?

Appendix H: Field Notes

Please note, the actual information pertaining to the above appendix was omitted due to personal and confidential information.

This relates to pages 215 to 226

Appendix I: Ethical Clearance, University of Pretoria

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

1 April 2014

Dear Prof Maree

Project:	**Family processes and coping strategies of families of adolescents diagnosed with epilepsy**
Researcher:	**K Erasmus**
Supervisor:	**Prof T Bakker**
Department:	**Psychology**
Reference:	**94414093**

Thank you for your response to the Committee's correspondence of 17 February 2014.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 1 April 2014. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof. Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: karen.harris@up.ac.za

Appendix J: Permission – Life Healthcare Group

Life Group
HEALTH CARE

Life Healthcare Head Office
Oxford Manor, 21 Chaplin Road, Illovo 2196
Private Bag X13, Northlands 2116, South Africa
Telephone +27 11 219 9000
Telefax +27 11 219 9001
www.lifehealthcare.co.za

13 June 2014

ATTENTION: KARLIEN ERASMUS

APPROVAL FOR RESEARCH STUDY

TITLE: Family processes and coping strategies of families of adolescents diagnosed with epilepsy.

Our previous correspondence refers.

The Research Committee of Life Healthcare has granted permission for your study to be conducted within the company's facilities. Please present this letter to the Hospital Manager of each institution when seeking permission to use facilities.

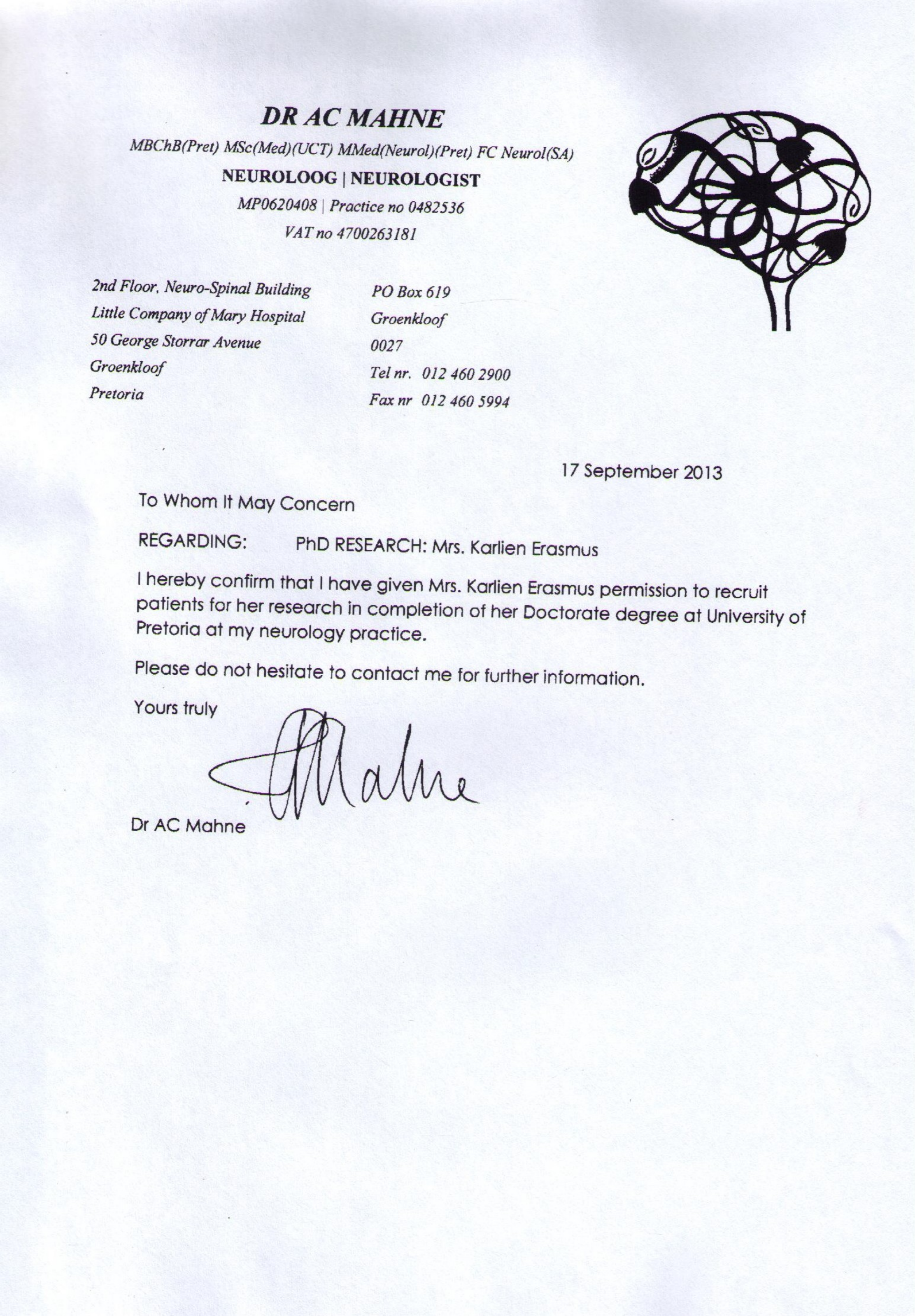
We look forward to seeing the results of your research once it is completed.

Yours sincerely

Anne Roodt
Education Specialist
Life College of Learning

Life Healthcare Group (Proprietary) Limited
Reg. no. 2003/024367/07 Registered address Oxford Manor, 21 Chaplin Road, Illovo 2196, Private Bag X13, Northlands 2116
Directors: A Meyer (Chief Executive Officer), CLW Bekker, D Scheublé, PP van der Westhuizen

Appendix K: Permission – Participating Neurologists



DR AC MAHNE

MBChB(Pret) MSc(Med)(UCT) MMed(Neurol)(Pret) FC Neurol(SA)

NEUROLOOG | NEUROLOGIST

MP0620408 | Practice no 0482536

VAT no 4700263181

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Little Company of Mary Hospital
50 George Storrar Avenue
Groenkloof
Pretoria

PO Box 619
Groenkloof
0027
Tel nr. 012 460 2900
Fax nr 012 460 5994

17 September 2013

To Whom It May Concern

REGARDING: PhD RESEARCH: Mrs. Karlien Erasmus

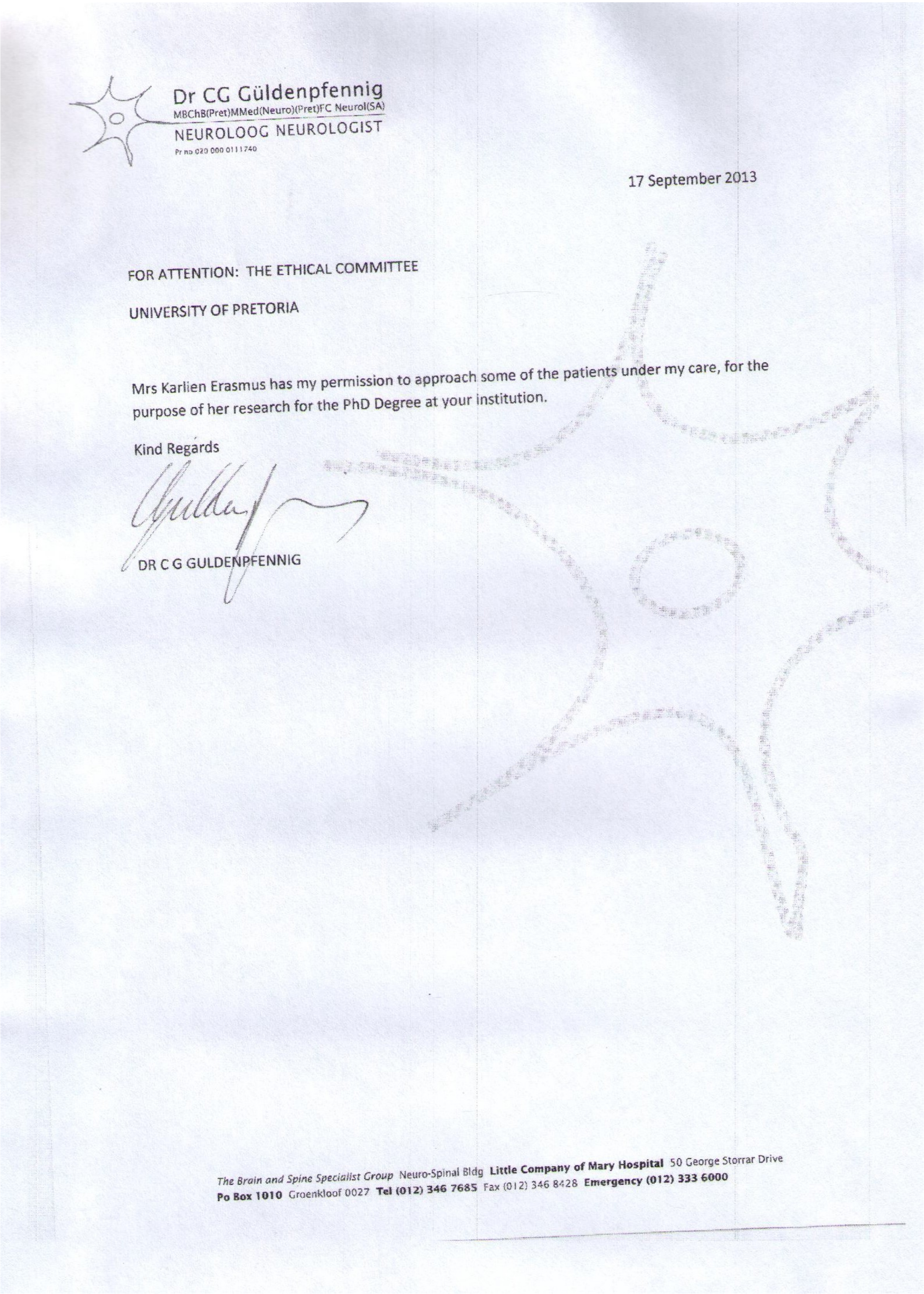
I hereby confirm that I have given Mrs. Karlien Erasmus permission to recruit patients for her research in completion of her Doctorate degree at University of Pretoria at my neurology practice.

Please do not hesitate to contact me for further information.

Yours truly

Mahne

Dr AC Mahne



Dr CG Güldenpfennig
MBChB(Pret)MMed(Neuro)(Pret)FC Neurol(SA)
NEUROLOOG NEUROLOGIST
Pr no 020 000 0111740

17 September 2013

FOR ATTENTION: THE ETHICAL COMMITTEE

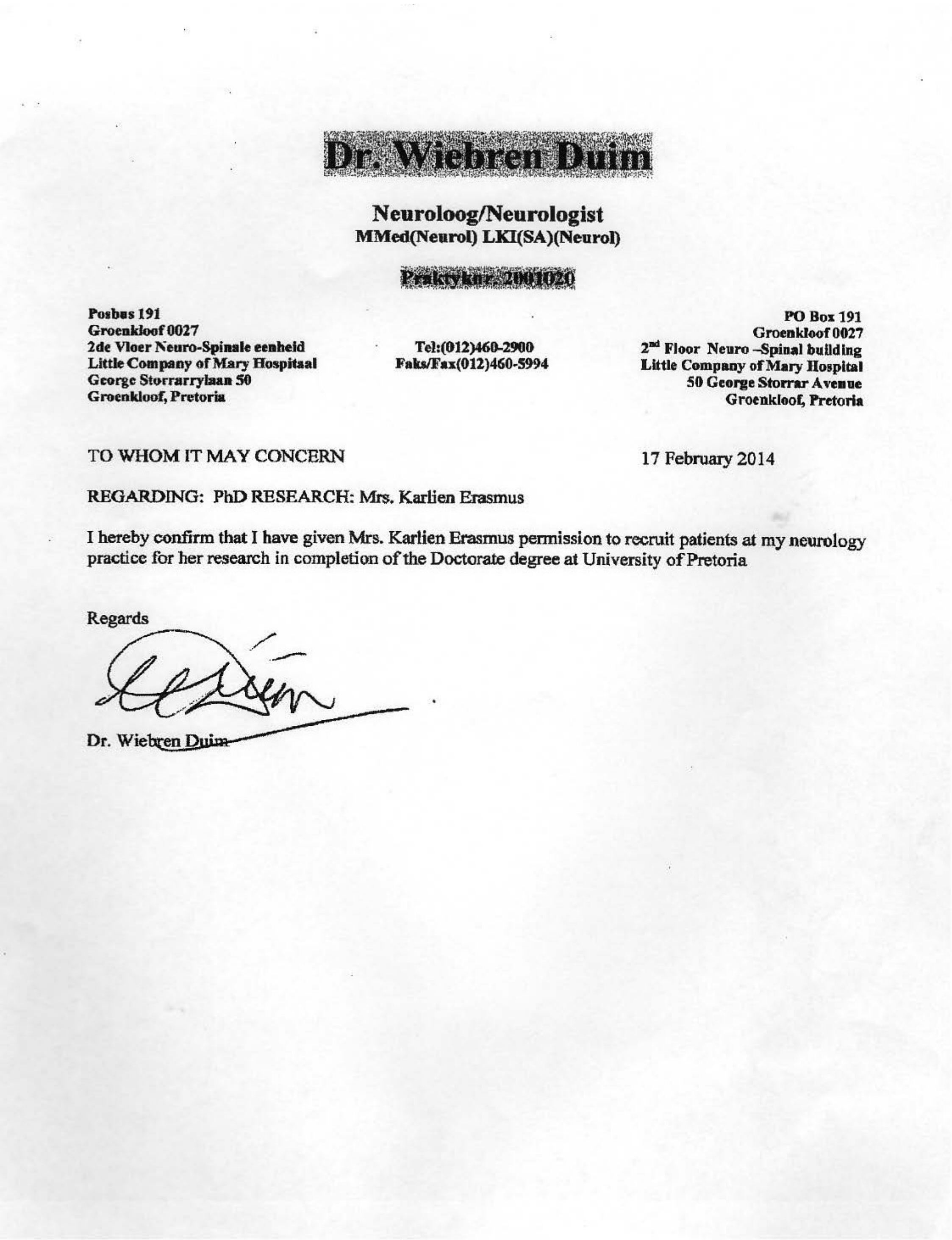
UNIVERSITY OF PRETORIA

Mrs Karlien Erasmus has my permission to approach some of the patients under my care, for the purpose of her research for the PhD Degree at your institution.

Kind Regards

DR C G GULDENPFENNIG

The Brain and Spine Specialist Group Neuro-Spinal Bldg **Little Company of Mary Hospital** 50 George Storrar Drive
Po Box 1010 Groenkloof 0027 **Tel (012) 346 7685** Fax (012) 346 8428 **Emergency (012) 333 6000**



Dr. Wiebren Duim

Neuroloog/Neurologist
MMed(Neurol) LKI(SA)(Neurol)

Praktyknr: 2001020

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Little Company of Mary Hospital
50 George Storrar Avenue
Groenkloof, Pretoria

TO WHOM IT MAY CONCERN

17 February 2014

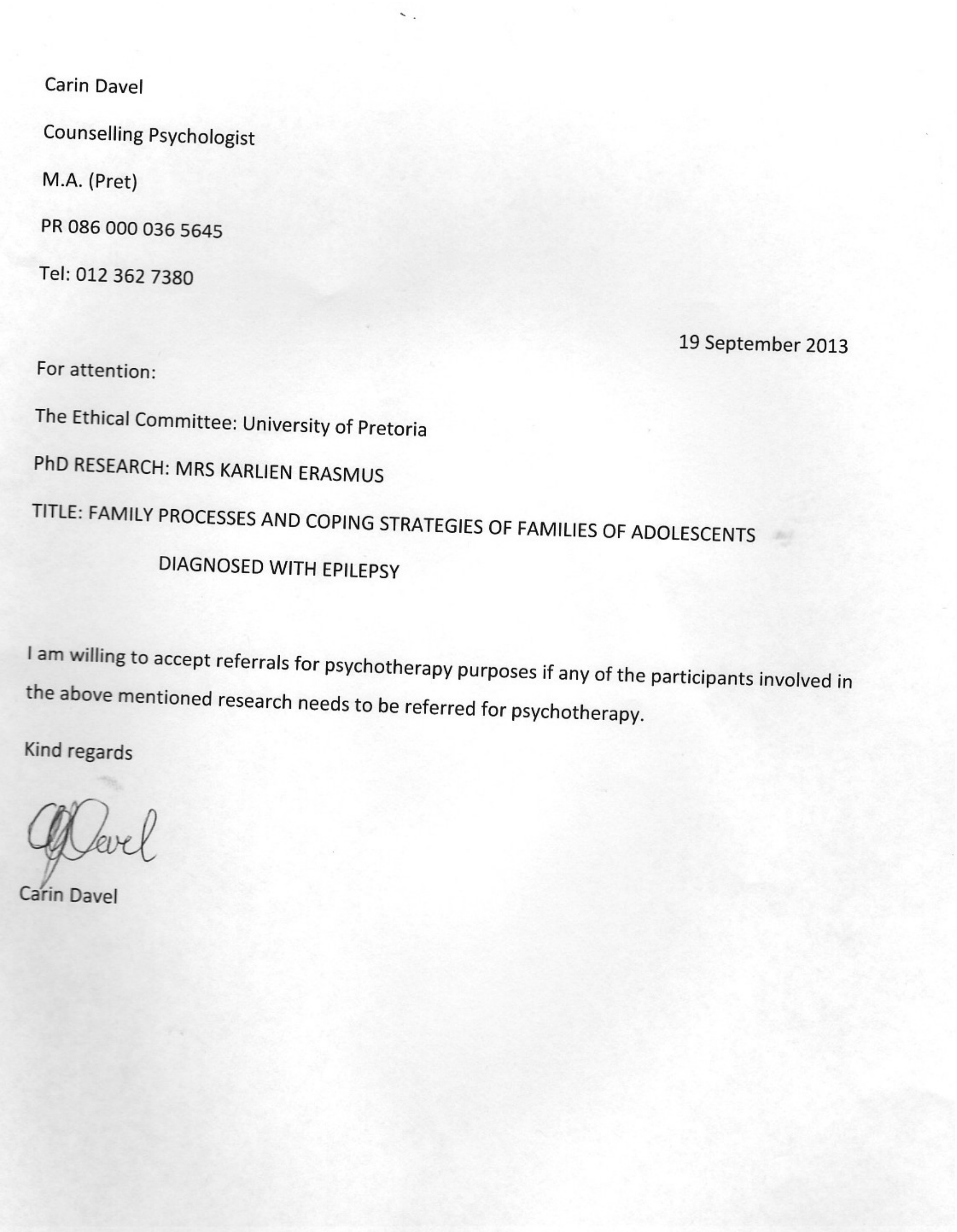
REGARDING: PhD RESEARCH: Mrs. Karlien Erasmus

I hereby confirm that I have given Mrs. Karlien Erasmus permission to recruit patients at my neurology practice for her research in completion of the Doctorate degree at University of Pretoria

Regards

Dr. Wiebren Duim

Appendix L: Permission – Supporting Psychologist



Carin Davel

Counselling Psychologist

M.A. (Pret)

PR 086 000 036 5645

Tel: 012 362 7380

19 September 2013

For attention:

The Ethical Committee: University of Pretoria

PhD RESEARCH: MRS KARLIEN ERASMUS

TITLE: FAMILY PROCESSES AND COPING STRATEGIES OF FAMILIES OF ADOLESCENTS DIAGNOSED WITH EPILEPSY

I am willing to accept referrals for psychotherapy purposes if any of the participants involved in the above mentioned research needs to be referred for psychotherapy.

Kind regards

Carin Davel

Appendix M: Informed Consent for Parents & Adolescents

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

ACULTY OF HUMANITIES
DEPARTMENT OF PSYCHOLOGY

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH - PARENTS

Researchers' detail:

Karlien Erasmus (Counselling Psychologist)

karlien@erasmustherapy.com or 012-362-7380

Dear participant

I am a Counselling Psychologist, currently completing a Ph.D. at the University of Pretoria under the promotion of Prof Terri Bakker.

1. Title and purpose of the research

The title of the research is "Family processes and coping strategies of families of adolescents diagnosed with epilepsy." The general purpose of the research is to explore the family processes and coping strategies of your family including your adolescent child who is diagnosed with epilepsy.

It is believed that this research will contribute to current knowledge in the field of psychology and may be used proactively. Results may assist medical specialists to treat patients like your child more effectively taking in to consideration both the emotional aspects as well as the physiological or medical aspects when treating an adolescent patient with epilepsy.

2. Procedures

Your adolescent child (age 13 to 18 years) diagnosed with epilepsy as well as his or her family members (parents or guardian and siblings or any other family member living with the patient and seen by the patient as part of his or her core family) will be invited to participate in the research. Gathering of data will take place on the same day as when your child will come to see his or her neurologist for a follow-up appointment. Participation will entail a once off appointment with the researcher:

2.1 There will be an interview with you and your family, including your adolescent child diagnosed with epilepsy – duration of ± 1 hour to 1 hour 30 minutes. Siblings from the age of 5 years old can participate in the interview. This interview will be recorded on video or DVD.

2.2 Then it will take another 30 minutes to complete a number of questionnaires.

3. Risks and discomforts

No physical or emotional risks are foreseen although some heightened emotional awareness might arise because of the nature of the topic being discussed. If at any time you feel that sensitive material is touched upon, or if any discomfort arises, counseling or therapy by an independent therapist will be available free of charge. A rest period can be given between the interview and questionnaires if you feel you get tired.

4. Benefits

Benefits might include becoming aware of family processes and to understand and make sense of your family's' emotional experiences of family matters. By becoming aware of the above mentioned might assist you and your family to manage the diagnosis of epilepsy on an emotional level. There will be no financial gain in participating in the research.

5. Participants' rights

Participation is voluntary and you may withdraw from participation in the study at any time and without negative consequences. All records and data will be destroyed if you choose to withdraw.

6. Confidentiality

All information will be treated as confidential and anonymity will be assured by not including any identifiable detail and by using numbers, and not names, when referring to the participants. The data will be destroyed should you withdraw from the research. The persons that will have access to the research data will be the researcher and the researchers' supervisor of the University of Pretoria.

7. Right of access to researcher

You can make contact with me at any time during the research process (contact detail on this letter) should any doubt arise and should you seek clarity on any issue.

8. Further research

Data collected for research purposes will be stored at the University of Pretoria for 15 years. You hereby also give consent that data can be used for further research.

I, (name)________________________hereby give permission to participate in the research, I have received sufficient information and I have had the opportunity to discuss any uncertainty.

Participant (signature)________________________________

Signed at (place)________________________on (date)________________________

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

INFORMED ASSENT FOR PARTICIPATION IN RESEARCH – ADOLESCENTS

Researchers' detail:

Karlien Erasmus (Counselling Psychologist)

karlien@erasmustherapy.com or 012-362-7380

Dear participant,

I am a Counselling Psychologist busy doing a Doctoral degree at the University of Pretoria under the supervision of Prof Terri Bakker.

1. Title and purpose of the research

The title of the research is "Family processes and coping strategies of families of adolescents diagnosed with epilepsy." The goal of the research is to try to understand what you and your family are struggling with, how you are doing with this diagnosis in the family, and what you are doing to cope.

This research will possibly help to know how to help other young people and children diagnosed with epilepsy and their families. This can possibly also help doctors to know how to treat patients like you (or your brother or sister) better.

2. Procedures

The person who has been diagnosed with epilepsy as well as his or her family members will take part in this research. Your family members will be invited to participate in the research. This can include your parents or guardian, brothers and sisters or any other family member living with you or meaningful other in your life.

The information used for the research will be collected on the same day you (or your brother or sister) will see the neurologist for a follow-up appointment. You will only see me once for this purpose.

2.1 I will hold an interview with you and your family and it will take ± 1 hour to 1 hour 30 minutes. Your brothers and sisters from the age of 5 years old can participate in the interview. This interview will be recorded on video or DVD.

2.2 Then another 30 minutes or so of questionnaires and you are done!

3. Risks and discomforts

It is unlikely that you will experience any physical or emotional risk. If at any time you feel uncomfortable in any way, therapy by an independent (another) therapist will be available free of charge. You may rest between the interview and questionnaires if you feel tired.

4. Benefits

You may benefit by participating in this research by becoming aware of the processes in your family and understanding your family's emotional experiences better. This may help you and your family to cope better with the epilepsy. Unfortunately, you will not be paid to participate in this research.

5. Participants' rights

You participate out of your own free will and you may pull out at any time without it being a problem. All information given by you will be destroyed if you do not want to continue with the research.

6. Confidentiality

All information will be treated as confidential and no one will be able to identify who you are when looking at the information you gave me. Numbers, and not names, will be used when referring to you in the research. The information will be destroyed if you choose not participate any more. The people that will have access to the research information will be: The researcher (that's me) and my supervisor at the University of Pretoria.

7. Right of access to researcher

You can phone or e-mail me at any time during the research process (contact detail on this letter) if you feel you want to speak to me on any issue relating to the research.

8. Further research

Information collected for the research purposes will be stored at the University of Pretoria for 15 years. You hereby also give permission that this information can be used for further research.

(a) I (name of participant)_________________________hereby give permission to participate in the research, I understand what the research is about, and I have had the opportunity to ask questions where I felt it was necessary.

Child (signature)____________________________

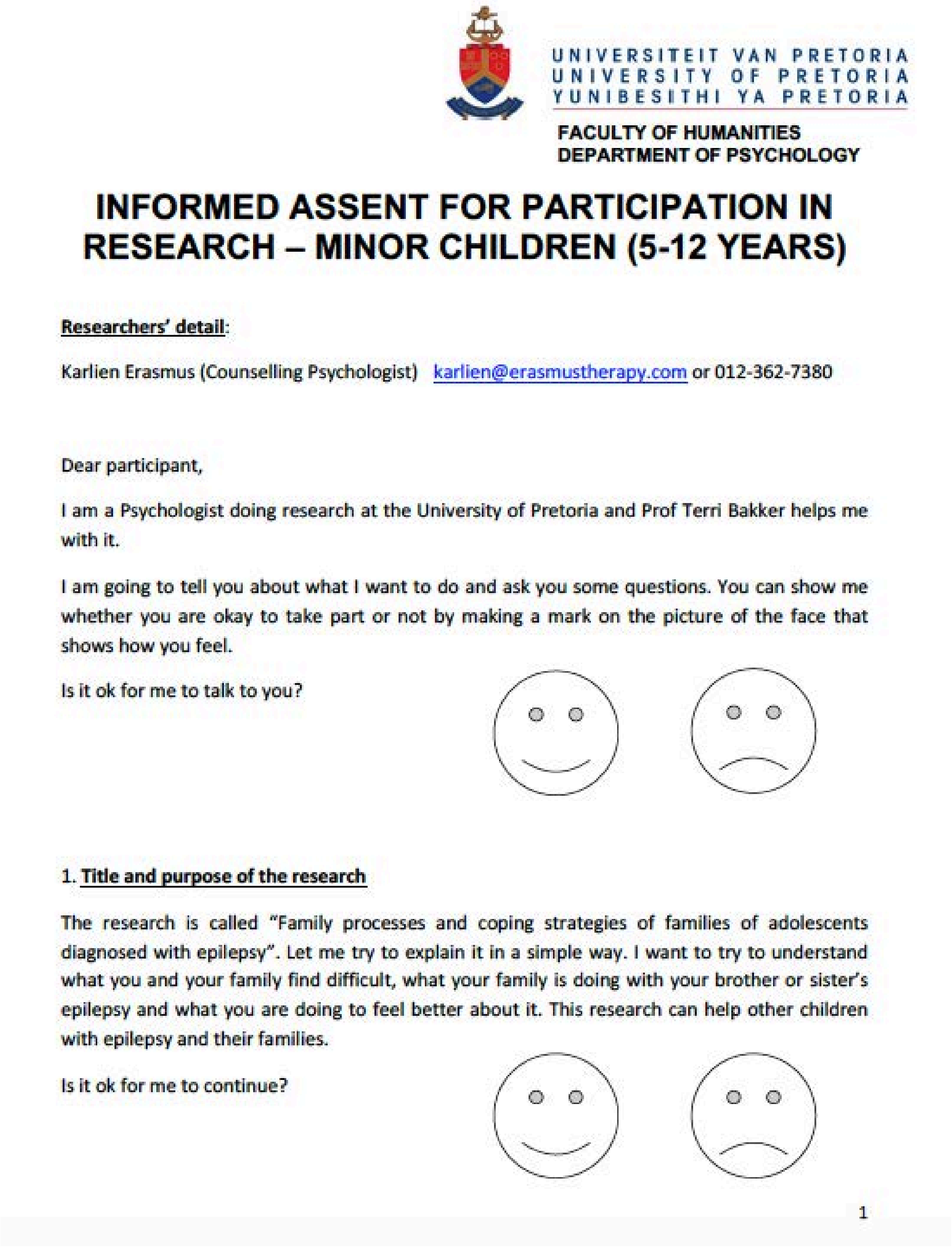
Signed at (place)_____________________on (date)________________________

(b) I, (name of parent or guardian)________________________hereby give permission for (name of minor participant)__________________________to participate in the research, I have received sufficient information, and I have had the opportunity to discuss any uncertainty.

Parent or guardian (signature)_____________________________

Signed at (place)_____________________on (date)________________________

Appendix N: Informed Assent for Minor Childern



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

FACULTY OF HUMANITIES
DEPARTMENT OF PSYCHOLOGY

INFORMED ASSENT FOR PARTICIPATION IN RESEARCH – MINOR CHILDREN (5-12 YEARS)

Researchers' detail:

Karlien Erasmus (Counselling Psychologist) karlien@erasmustherapy.com or 012-362-7380

Dear participant,

I am a Psychologist doing research at the University of Pretoria and Prof Terri Bakker helps me with it.

I am going to tell you about what I want to do and ask you some questions. You can show me whether you are okay to take part or not by making a mark on the picture of the face that shows how you feel.

Is it ok for me to talk to you?

☺ ☹

1. Title and purpose of the research

The research is called "Family processes and coping strategies of families of adolescents diagnosed with epilepsy". Let me try to explain it in a simple way. I want to try to understand what you and your family find difficult, what your family is doing with your brother or sister's epilepsy and what you are doing to feel better about it. This research can help other children with epilepsy and their families.

Is it ok for me to continue?

☺ ☹

2. **What we are going to do**

Your brother or sister with epilepsy as well as your family members will be invited to participate. This can be your father, mother, sisters, and brothers.

We will meet to talk on the same day your brother or sister will see his or her doctor. You will only see me once to do this.

2.1 I will talk to you and your family and we will be busy for a little while. It will recorded this on video or DVD.

Will this be okay for you?

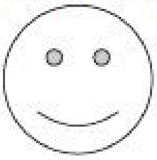
2.2 Then your father or mother will ask the family some questions and write the answers down on a piece of paper and then you are done!

Will this be okay for you?

3. **Difficult things**

It is not supposed to be difficult or bad for you. If you feel uncomfortable, there will be someone to talk to about that. You may take a rest when you feel tired.

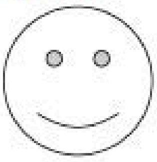
Is this okay with you?



4. **Benefits**

It may feel nice to you to participate in this research and you may get to know your family better. This may help you and your family with the epilepsy.

Will this work for you?



5. **You can choose**

You choose if you want to participate and may stop at any time without it being a problem. All information given by you will be destroyed if you do not want to continue with the research.

Is this okay with you? ☺ ☹

6. **Confidentiality**

Everything you said will be kept a secret and no one will know that it was you that said that when looking at the information you gave me. I will use a numbers, and not your name, when I refer to you in the research. Your information will be destroyed if you choose to stop and not continue with the research. It will only be me and my supervisor at the University of Pretoria that will see your information.

Is this okay with you? ☺ ☹

7. **You can contact me**

You can phone or e-mail me, or ask your father or mother to phone or e-mail me at any time during the research if you feel you want to speak to me on anything about the research.

Will this work for you? ☺ ☹

8. **Further research**

Information you give me will be stored at the University of Pretoria for 15 years. Will it be okay with you if other people want to use this information for other research?

☺ ☹

(a) (My name) ______________________ say "yes" to participate in the research.

(b) I, (name of parent or guardian) ________________________ hereby give permission for (name of minor participant) ________________________ to participate in the research, I have received sufficient information, and I have had the opportunity to discuss any uncertainty.

Parent or guardian (signature)____________________________

Signed at (place)_____________________ on (date)________________________

Appendix O: Description of the Family Profile

Family 1

Family Satisfaction Scale (FSS)

Table 1

Scores of Subscales of FSS for Family 1

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	82	82	**79 – High**
Patient	55	19	**37 - Moderate**

The family has a total Satisfaction score that is “high” and means that the family members are satisfied with most aspects of their family. The patient scored “moderate” which means that the patient is somewhat satisfied and enjoys some aspects of his or her family.

Family Functioning Scale (FFS)

Table 2

Scores of Subscales of FFS for Family 1

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	29	16	34	**79**
Patient	27	14	39	**80**

According to the family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing. According to the patient, their strengths are coping, then family identity and less on information sharing.

Family Hardiness Index (FHI)

Table 3

Scores for Subscales for FHI for Family 1

Subscale	Family	Patient
Commitment	24	32
Challenge	17	18
Control	7	10
Confidence	6	14
Total Hardiness	**54 – Average**	**74 – High**

According to the FHI scoring procedures a higher total will indicate a higher hardiness. Hardiness is closely linked to the basic strength families call upon to manage the hardships and difficulties of transitions and crises (Patterson in Mc Cubbin, McCubbin & Thompson, 1991). The researcher distinguished three categories 0-33% "low," 34-66% "average" and 67-100% "high" to ease interpretation. For Family 1 their hardiness is "average" and for the patient their hardiness is "high."

Family Assessment Device (FAD)

Table 4

Scores of FAD for Family 1

Subscale	Family	Patient
Problem solving	1.40 – Healthy	1.40 – Healthy
Communication	1.67 – Healthy	2.17 – Middle
Roles	2.13 – Middle	2.13 – Middle
Affective responsiveness	2.50 – Middle	1.83 – Healthy
Affective involvement	2.86 – Middle	2.14 – Middle
Behaviour control	2.00 – Healthy	1.78 – Healthy
General functioning	1.50 – Healthy	1.42 – Healthy

The overall family functioning of family members of Family 1 is "healthy." The family members also functions "healthy" on Problem Solving, Communication and Behavioural control. The overall family functioning according to the patient is also "healthy," and the family functions "healthy" on Problem solving, Affective Responsiveness and Behavioural Control.

Family 2

FSS

Table 5

Scores of FSS for Family 2

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	61	88	**73 – High**
Patient	16	85	**40 - Moderate**

The family has a total Satisfaction score that is "high" and means that the family members are satisfied with most aspects of their family. The patient scored "moderate" which means that the patient is somewhat satisfied and enjoys some aspects of his or her family.

FFS

Table 6

Scores of FFS for Family 2

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	25	12	40	**77**
Patient	22	14	39	**75**

According to the family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing. According to the patient, their strengths are coping, then family identity and less on information sharing.

FHI

Table 7

Scores for FHI for Family 2

Subscale	Family	Patient
Commitment	22	28
Challenge	13	11
Control	10	9
Confidence	16	6
Total Hardiness	**66 – Average**	**54 – Average**

For Family 2 their hardiness is “average” and for the patient their hardiness is “average.”

FAD

Table 8

Scores of FAD for Family 2

Subscale	Family	Patient
Problem solving	2.40 – Middle	2.20 – Middle
Communication	2.00 – Healthy	2.00 – Healthy
Roles	2.50 – Middle	3.25 – Unhealthy
Affective responsiveness	2.33 – Middle	3.00 – Unhealthy
Affective involvement	1.86 – Healthy	2.00 – Healthy
Behaviour control	2.00 – Healthy	2.11 – Middle
General functioning	2.08 – Middle	2.17 – Middle

The overall family functioning of family members of Family 2 is in the “middle” between healthy and unhealthy and the family members functions “healthy” on Communication, Affective Involvement and Behavioural control. The overall family functioning according to the patient is also in the “middle” between healthy and unhealthy, and the family functions “healthy” on Communication and Affective Involvement and “unhealthy” on Roles and Affective Responsiveness.

Family 03

<u>FSS</u>

Table 9

Scores of FSS for Family 3

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	1	34	**1 – Very low**
Patient	1	19	**1 – Very low**

The family and patient have a total Satisfaction score that is “low” and means that the family members and the patient are very dissatisfied and are concerned about their family.

<u>FFS</u>

Table 10

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	23	9	36	**68**
Patient	17	6	32	**55**

According to the family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing. According to the patient, their strengths are coping, then family identity and less on information sharing.

<u>FHI</u>

Table 11

Scores for FHI for Family 3

Subscale	Family	Patient
Commitment	29	31
Challenge	16	17
Control	9	9
Confidence	12	14
Total Hardiness	**66 – Average**	**71 – High**

For Family 3 their hardiness is “average” and for the patient their hardiness is “high.”

FAD

Table 12

Scores for FAD for Family 3

Subscale	Family	Patient
Problem solving	1.80 – Healthy	3.00 – Unhealthy
Communication	2.83 – Middle	2.67 – Middle
Roles	2.75 – Middle	2.88 – Middle
Affective responsiveness	2.67 – Middle	2.50 – Middle
Affective involvement	2.71 – Healthy	2.29 – Middle
Behaviour control	1.67 – Healthy	1.56 – Healthy
General functioning	2.58 – Middle	1.75 – Healthy

The overall family functioning of family members of Family 3 is in the "middle" between healthy and unhealthy and functions "healthy" on Problem Solving and Behavioural control. The overall family functioning according to the patient is "healthy," and the family functions "healthy" on Behavioural Control and "unhealthy" on Problem Solving.

Family 4

FSS

Table 13

Scores for FSS for Family 4

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	94	94	**94 – Very high**
Patient	94	91	**91 – Very high**

The family and patient has a total Satisfaction score that is "very high" and means that the family members and patient are very satisfied and really enjoy most aspects of their family.

FFS

Table 14

Scores for FFS for Family 4

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	32	15	44	**91**
Patient	28	14	27	**69**

According to family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing. According to the patient, their strengths are coping, then family identity and less on information sharing.

FHI

Table 15

Scores for FHI for Family 4

Subscale	Family	Patient
Commitment	31	27
Challenge	18	15
Control	6	9
Confidence	15	16
Total Hardiness	**70 – High**	**67 – High**

For Family 4 their hardiness is "high" and for the patient their hardiness is "high."

FAD

Table 16

Scores for FAD for Family 4

Subscale	Family	Patient
Problem solving	1.80 – Healthy	1.40 – Healthy
Communication	1.67 – Healthy	1.67 – Healthy
Roles	2.00 – Healthy	2.38 – Middle
Affective responsiveness	1.83 – Healthy	2.50 – Middle
Affective involvement	1.71 – Healthy	2.43 – Middle
Behaviour control	1.22 – Healthy	1.44 – Healthy
General functioning	1.42 - Healthy	1.42 – Healthy

The overall family functioning of family members of Family 4 is "healthy," and family members function "healthy" on all other scales being Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement and Behavioural control. The overall family functioning according to the patient is also "healthy," and the family functions "healthy" on Problem Solving, Communication, and Behavioural Control.

Family 5

FSS

Table 17

Scores for FSS for Family 5

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	28	91	**61 – High**
Patient	55	91	**70 – High**

The family, and patient has a total Satisfaction score that is "high" and means that the family members and the patient are satisfied with most aspects of their family.

FFS

Table 18

Scores for FFS for Family 5

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	28	12	40	**80**
Patient	28	11	40	**79**

According to family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing. According to the patient, their strengths are coping, then family identity and less on information sharing.

FHI

Table 19

Scores for FHI for Family 5

Subscale	Family	Patient
Commitment	31	29
Challenge	11	18
Control	10	7
Confidence	16	16
Total Hardiness	**68 – High**	**70 – High**

For Family 5 their hardiness is "high" and for the patient their hardiness is "high."

FAD

Table 20

Scores for FAD for Family 5

Subscale	Family	Patient
Problem solving	2.00 – Healthy	1.40 – Healthy
Communication	2.17 – Middle	2.33 – Middle
Roles	2.50 – Middle	2.63 – Middle
Affective responsiveness	1.50 – Healthy	2.50 – Middle
Affective involvement	2.43 – Middle	1.71 – Healthy
Behaviour control	2.11 – Middle	1.89 – Healthy
General functioning	1.67 - Healthy	2.00 – Healthy

The overall family functioning of family members of Family 5 is “healthy” and family members function “healthy” on Problem Solving and Affective Responsiveness. The overall family functioning according to the patient is also “healthy,” and the family function “healthy” on Problem Solving, Affective Involvement, and Behavioural Control.

Family 6

FSS

Table 21

Scores for FSS for Family 6

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	13	73	**37 – Moderate**
Patient	16	37	**19 – Very low**

The family has a total Satisfaction score that is “moderate” and means that the family members are somewhat satisfied and enjoy some aspects of their family. For the patient it scored “very low” which means that the patient is very dissatisfied and is concerned about his or her family.

FFS

Table 22

Scores for FFS for Family 6

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	32	12	41	**85**
Patient	12	3	22	**37**

According to the family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing. According to the patient, their strengths are coping, then family identity and less on information sharing.

FHI

Table 23

Scores for FHI for Family 6

Subscale	Family	Patient
Commitment	31	18
Challenge	17	13
Control	5	9
Confidence	16	13
Total Hardiness	**69 – High**	**53 – Average**

For Family 6 their hardiness is “high” and for the patient their hardiness is “average.”

FAD

Table 24

Scores of FAD for Family 6

Subscale	Family	Patient
Problem solving	2.00 – Healthy	3.00 – Middle
Communication	2.00 – Healthy	2.83 – Middle
Roles	2.00 – Healthy	2.13 – Middle
Affective responsiveness	2.17 – Middle	3.33 – Unhealthy
Affective involvement	2.29 – Middle	2.86 – Middle
Behaviour control	1.56 – Healthy	2.11 – Middle
General functioning	2.17 - Middle	2.92 – Middle

The overall family functioning of family members of Family 6 is in the “middle” between healthy and unhealthy and the family members functions “healthy” on Problem Solving and Communication. The overall family functioning according to the patient is in the “middle” between healthy and unhealthy, and the family functions “unhealthy” on Affective Responsiveness.

Family 07

FSS

Table 25

Scores of FSS for Family 7

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	37	88	**61 – High**

Patient	1	19	**1 – Very low**

The family has a total Satisfaction score that is "high" and means that the family members are satisfied with most aspects of their family. The patient scored "very low" which means that the patient is very dissatisfied and is concerned about his or her family.

<u>FFS</u>

Table 26

Scores of FSS for Family 7

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	30	14	42	**86**
Patient	19	8	26	**53**

According to the family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing. According to the patient, their strengths are coping, then family identity and less on information sharing.

<u>FHI</u>

Table 27

Scores of FHI for Family 7

Subscale	Family	Patient
Commitment	31	14
Challenge	12	9
Control	10	8
Confidence	16	11
Total Hardiness	**69 – High**	**42 – Average**

For Family 07 their hardiness is "high" and for the patient their hardiness is "average."

<u>FAD</u>

Table 28

Scores of FAD for Family 7

Subscale	Family	Patient
Problem solving	2.20 – Middle	2.60 – Middle
Communication	2.00 – Healthy	3.83 – Unhealthy
Roles	2.25 – Middle	2.88 – Middle
Affective responsiveness	1.83 – Healthy	3.33 – Unhealthy
Affective involvement	1.57 – Healthy	2.43 – Middle
Behaviour control	1.67 – Healthy	2.89 – Middle

General functioning	1.75 - Healthy	2.58 – Middle

The overall family functioning of family members of Family 6 is "healthy," and the family members function "healthy" on Communication, Affective responsiveness, Affective involvement, and Behavioural control. The overall family functioning according to the patient is in the "middle" between healthy and unhealthy and the family functions "unhealthy" on Communication and Affective Responsiveness.

Family 08

FSS

Only one family member participated in the research. The patient did not want to participate and therefore no information regarding a patient questionnaire is available.

Table 29

Scores of FSS for Family 8

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	28	19	**22 – Low**
Patient	No score	No score	**No score**

The family has a total Satisfaction score that is "low" and means that the family members are somewhat dissatisfied and have some concerns about their family.

FFS

Table 30

Scores of FFS for Family 8

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	28	14	37	**79**
Patient	No score	No score	No score	**No score**

According to the family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing.

FHI

Table 31

Scores of FHI for Family 8

Subscale	Family	Patient
Commitment	28	No score
Challenge	12	No score
Control	7	No score
Confidence	13	No score
Total Hardiness	**60 – Average**	**No score**

For Family 8 their hardiness is “average.”

FAD

Table 32

Scores of FAD for Family 8

Subscale	Family	Patient
Problem solving	1.80 – Healthy	No score
Communication	2.00 – Healthy	No score
Roles	2.38 – Middle	No score
Affective responsiveness	1.33 – Healthy	No score
Affective involvement	2.14 – Middle	No score
Behaviour control	1.67 – Healthy	No score
General functioning	1.67 – Healthy	No score

The overall family functioning of family members of Family 8 is “healthy” and the family members function “healthy” on Problem Solving, Communication, and Affective Responsiveness and Behavioural control.

Family 9

FSS

Table 33

Scores of FSS for Family 9

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	28	34	**28 – Low**
Patient	49	70	**55 - Moderate**

The family has a total Satisfaction score that is “low” and means that the family members are somewhat dissatisfied and have some concerns about their family. For the patient it scored “moderate” which means that the patient is somewhat satisfied and enjoys some aspects of his or her family.

FFS

Table 34

Scores of FFS for Family 9

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	23	9	33	**65**
Patient	17	14	29	**60**

According to family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing. According to the patient, their strengths are coping, then family identity and less on information sharing.

FHI

Table 35

Scores of FHI for Family 9

Subscale	Family	Patient
Commitment	26	17
Challenge	12	11
Control	9	4
Confidence	11	7
Total Hardiness	**58 – Average**	**39 - Low**

For Family 09 their hardiness is “average” and for the patient their hardiness is “low.”

FAD

Table 36

Scores of FAD for Family 9

Subscale	Family	Patient
Problem solving	2.20 – Middle	3.20 – Unhealthy
Communication	2.50 – Middle	2.17 – Middle
Roles	3.00 – Middle	2.38 – Middle
Affective responsiveness	2.17 – Middle	2.17 – Middle
Affective involvement	1.86 – Healthy	2.71 – Middle
Behaviour control	2.11 – Middle	2.78 – Middle
General functioning	2.25 - Middle	2.42 – Middle

The overall family functioning of family members of Family 9 is in the “middle” between healthy and unhealthy and the family members function “healthy” on Affective Involvement. The overall family functioning according to the patient is in the “middle” between healthy and unhealthy and the family functions “unhealthy” on Problem Solving.

Family 10

FSS

Table 37

Scores for FSS for Family 10

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	1	34	**1 – Very low**
Patient	19	61	**31 - Low**

The family has a total Satisfaction score that is “very low,” and it means that the family members are very dissatisfied, and concerned about their family. The patient scored “low” which means that the patient is somewhat dissatisfied and has concerns about his or her family.

FFS

Table 38

Scores of FFS for Family10

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	20	11	31	**62**
Patient	27	14	43	**84**

According to the family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing. According to the patient, their strengths are coping, then family identity and less on information sharing.

FHI

Table 39

Scores of FHI for Family 10

Subscale	Family	Patient
Commitment	26	27
Challenge	10	18
Control	10	10
Confidence	14	14
Total Hardiness	**60 – Average**	**69 - High**

For Family 10 their hardiness is “average” and for the patient their hardiness is “high.”

FAD

Table 40

Scores of FAD for Family 10

Subscale	Family	Patient
Problem solving	2.40 – Middle	1.80 – Healthy
Communication	2.33 – Middle	2.00 – Healthy
Roles	2.75 – Middle	2.50 – Middle
Affective responsiveness	2.50 – Middle	2.50 – Middle
Affective involvement	2.00 – Healthy	2.29 – Middle
Behaviour control	1.11 – Healthy	1.22 – Healthy
General functioning	2.58 - Middle	2.17 – Middle

The overall family functioning of family members of Family 10 is in the “middle” between healthy and unhealthy and the family members function “healthy” on Affective Involvement and Behavioural control. The overall family functioning according to the patient is in the “middle” between healthy and unhealthy and the family functions “healthy” on Problem Solving, Communication, and Behavioural Control.

Family 11

FSS

Table 41

Scores of FSS for Family 11

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	52	55	**52 - Moderate**
Patient	16	25	**16 – Very low**

The family has a total Satisfaction score that is “moderate” and means that the family members are somewhat satisfied and enjoy some aspects of their family. The patient scored “very low” which means that the patient is very dissatisfied and concerned about his or her family.

FFS

Table 42

Scores of FFS for Family 11

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**

Family	24	10	39	**73**
Patient	12	7	22	**41**

According to family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing. According to the patient, their strengths are coping, then family identity and less on information sharing.

FHI

Table 43

Scores of FHI for Family 11

Subscale	Family	Patient
Commitment	28	19
Challenge	13	9
Control	9	9
Confidence	10	6
Total Hardiness	**60 – Average**	**43 - Average**

For Family 11 their hardiness is “average” and for the patient their hardiness is “average.”

FAD

Table 44

Scores of FAD for Family 11

Subscale	Family	Patient
Problem solving	1.80 – Healthy	2.80 - Middle
Communication	2.50 – Middle	3.00 - Middle
Roles	2.75 – Middle	2.38 - Middle
Affective responsiveness	2.83 – Middle	3.17 - Unhealthy
Affective involvement	2.14 – Middle	2.86 - Middle
Behaviour control	1.78 – Healthy	2.67 - Middle
General functioning	2.58 - Middle	2.92 - Middle

The overall family functioning of family members of Family 11 is in the “middle” between healthy and unhealthy, and the family members functions “healthy” on Problem Solving and Behavioural control. The overall family functioning according to the patient is in the “middle” between healthy and unhealthy and the family functions “unhealthy” on Affective Responsiveness.

Family 12

FSS

Table 45

Scores of FSS for Family 12

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	91	91	**91 – Very high**
Patient	34	70	**46 - Moderate**

The family has a total Satisfaction score that is “very high” and means that the family members are very satisfied and really enjoy most aspects of their family. The patient scored “moderate” which means that the patient is somewhat satisfied and enjoys some aspects of his or her family.

FFS

Table 46

Scores of FFS for Family 12

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	27	13	40	**80**
Patient	20	9	37	**66**

According to family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing. According to the patient, their strengths are coping, then family identity and less on information sharing.

FHI

Table 47

Scores of FHI for Family 12

Subscale	Family	Patient
Commitment	30	25
Challenge	16	15
Control	9	9
Confidence	12	10
Total Hardiness	**67 – High**	**59 - Average**

For Family 12 their hardiness is “high” and for the patient their hardiness is “average.”

FAD

Table 48

Scores of FAD for Family 12

Subscale	Family	Patient
Problem solving	1.80 – Healthy	2.00 – Healthy
Communication	2.17 – Middle	2.00 – Healthy
Roles	1.75 – Healthy	2.75 – Middle
Affective responsiveness	2.00 – Healthy	2.17 – Middle
Affective involvement	2.00 – Healthy	2.29 – Middle
Behaviour control	1.33 – Healthy	2.22 – Middle
General functioning	1.33 – Healthy	2.42 – Middle

The overall family functioning of family members of Family 12 is “healthy” and the family members functions “healthy” on Problem Solving, Roles, Affective Responsiveness, and Affective Involvement and Behavioural control. The overall family functioning according to the patient is in the “middle” between healthy and unhealthy, and the family functions “healthy” on Problem Solving and Communication.

Family 13

FSS

Table 49

Scores of FSS for Family 13

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	19	73	**43 – Moderate**
Patient	No score	No score	**No score**

The family has a total Satisfaction score that is “moderate,” means that the family is somewhat satisfied, and enjoys some aspects of their family.

FFS

Table 50

Scores of FFS for Family 13

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	26	12	34	**72**
Patient	No scores	No scores	No scores	**No scores**

According to the family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing.

FHI

Table 51

Scores of FHI for Family 13

Subscale	Family	Patient
Commitment	29	No scores
Challenge	13	No scores
Control	10	No scores
Confidence	16	No scores
Total Hardiness	**68 – High**	**No scores**

For Family 13 their hardiness is "high."

FAD

Table 52

Scores of FAD for Family 13

Subscale	Family	Patient
Problem solving	1.60 – Healthy	No scores
Communication	1.67 – Healthy	No scores
Roles	1.50 – Healthy	No scores
Affective responsiveness	1.83 – Healthy	No scores
Affective involvement	1.43 – Healthy	No scores
Behaviour control	1.22 – Healthy	No scores
General functioning	1.25 – Healthy	No scores

The overall family functioning of family members of Family 13 is "healthy" and the family members function "healthy" on all scales, which is Problem Solving, Communication, Roles, Affective responsiveness, Affective Involvement and Behavioural control.

Family 14

FSS

Table 53

Scores of FSS for Family 14

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	76	94	**88 – Very high**
Patient	64	76	**67 – High**

The family has a total Satisfaction score that is “very high” and means that the family members are very satisfied and really enjoy most aspects of their family. For the patient it scored “high” which means that the patient is satisfied with most aspects of his or her family.

FFS

Table 54

Scores of FFS for Family 14

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	28	13	39	**80**
Patient	26	11	28	**65**

According to the family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing. According to the patient, their strengths are coping, then family identity and less on information sharing.

FHI

Table 55

Scores of FHI for Family 14

Subscale	Family	Patient
Commitment	32	26
Challenge	16	17
Control	9	8
Confidence	13	14
Total Hardiness	**70 – High**	**65 - Average**

For Family 14 their hardiness is “high” and for the patient their hardiness is “average.”

FAD

Table 56

Scores of FAD for Family 14

Subscale	Family	Patient
Problem solving	1.20 – Healthy	2.00 – Healthy
Communication	1.50 – Healthy	2.17 – Middle
Roles	1.75 – Healthy	2.38 – Middle
Affective responsiveness	2.00 – Healthy	1.67 – Healthy
Affective involvement	1.29 – Healthy	2.43 – Middle
Behaviour control	1.11 – Healthy	1.44 – Healthy
General functioning	1.25 – Healthy	1.50 – Healthy

The overall family functioning of family members of Family 13 is “healthy” and the family members function “healthy” on all scales, which is Problem Solving, Communication, Roles, Affective Responsiveness, and Affective Involvement and Behavioural control. The overall family functioning according to the patient is “healthy” and the family functions “healthy” on Problem Solving, Affective Responsiveness, and Behavioural Control.

Family 15

FSS

Table 57

Scores of FSS for Family 15

Family/Patient	Cohesion	Adaptability	**Total satisfaction**
Family	37	55	**43 - Moderate**
Patient	70	94	**85 - High**

The family has a total Satisfaction score that is “moderate” and means that the family members are somewhat satisfied and enjoy some aspects of their family. The patient scored “high” which means that the patient is satisfied with most aspects of his or her family.

FFS

Table 58

Scores of FFS for Family 15

Family/Patient	Family identity	Information sharing	Coping	**Total functioning**
Family	18	10	27	**55**
Patient	27	11	36	**74**

According to the family the strengths and capabilities of this family lies firstly in their coping, then in their family identity and less on information sharing. According to the patient, their strengths are coping, then family identity and less on information sharing.

FHI

Table 59

Scores of FHI for Family 15

Subscale	Family	Patient

Commitment	27	26
Challenge	10	16
Control	7	8
Confidence	13	12
Total Hardiness	**57 – Average**	**62 - Average**

For Family 15 their hardiness is “high” and for the patient their hardiness is “average.”

FAD

Table 60

Scores of FAD for Family 15

Subscale	Family	Patient
Problem solving	2.20 – Middle	2.20 – Middle
Communication	2.17 – Middle	2.17 – Middle
Roles	2.75 – Middle	2.50 – Middle
Affective responsiveness	2.00 – Healthy	2.00 – Healthy
Affective involvement	2.57 – Middle	2.14 – Middle
Behaviour control	2.11 – Middle	1.89 – Healthy
General functioning	2.17 – Middle	1.92 – Healthy

The overall family functioning of family members of Family 15 is in the middle between healthy and unhealthy and the family members function healthy on Affective Responsiveness. The overall family functioning according to the patient is healthy and the family functions healthy on Affective Responsiveness and Behavioural Control.

Appendix P: Results per Family, and Family as a Group

Descriptive statistics for family members and patients

Family questionnaire - statistical analysis in preparation form comparisons between family and patient (n = 15)

Here are descriptive statistics for all the subscales and the average scores and sub scores for each of the four scales for 15 participants (families).

Table 1

Family questionnaire n=15 Section B Descriptive statistics

FSS Subscales	Mean	Standard deviation	Minimum	Maximum	25th percentile	Median	75th percentile
Cohesion	43.20	31.25	1	94	19.00	37.00	76.00
Adaptability	67.00	26.25	19	94	34.00	73.00	91.00
Total	**51.60**	**30.44**	**1**	**94**	**28.00**	**52.00**	**79.00**

Table 2

Family questionnaire n = 15 Section C Descriptive statistics

FFS Subscales	Mean	Standard deviation	Minimum	Maximum	25th percentile	Median	75th percentile
Commitment	6.80	1.15	5	8	6.00	7.00	8.00
Appreciation	6.13	1.55	3	8	5.00	6.13	8.00
Time	6.00	1.60	3	8	5.00	6.00	8.00
Sense of purpose	7.27	1.34	4	8	6.00	8.00	8.00
Congruence	6.67	1.40	4	8	6.00	7.00	8.00
Communication	5.53	1.41	3	8	4.00	6.00	7.00
Role expectations	6.60	1.06	4	8	6.00	7.00	7.00
Coping 1	4.87	1.77	2	7	3.00	5.00	6.00
Coping 2	6.73	1.44	4	8	6.00	7.00	8.00
Problem solving	6.4	1.18	4	8	5.00	7.00	7.00
Positivism	6.87	1.25	5	8	6.00	7.00	8.00
Balance	5.40	1.35	4	8	4.00	5.00	7.00
Flexibility	6.87	1.60	3	8	7.00	7.00	8.00
Family identity	**26.20**	**4.07**	**18**	**32**	**23.00**	**27.00**	**29.00**
Information sharing	**12.13**	**2.10**	**9**	**16**	**10.00**	**12.00**	**14.00**
Coping/Resource mobilization	**37.13**	**4.60**	**27**	**44**	**34.00**	**39.00**	**40.00**
TOTAL	**75.47**	**9.69**	**55**	**91**	**68.00**	**79.00**	**80.00**

Table 3

Family questionnaire n = 15: Section D descriptive statistics

FHI Subscales	Mean	Standard deviation	Minimum	Maximum	25th percentile	Median	75th percentile
Commitment	28.67	2.35	24	32	27.00	29.00	31.00
Challenge	13.73	2.69	10	18	12.00	13.00	16.00
Control	8.47	1.64	5	10	7.00	9.00	10.00
Confidence	13.27	2.84	6	16	12.00	13.00	16.00
Total	**64.13**	**5.37**	**54**	**70**	**60.00**	**66.00**	**69.00**

Table 4

Family questionnaire n = 15: Section E descriptive statistics

FAD subscales	Mean	Standard deviation	Minimum	Maximum	25th percentile	Median	75th percentile
Problem solving	1.91	0.35	1.20	2.40	1.80	1.80	2.20
Communication	2.08	0.37	1.50	2.83	1.67	2.00	2.33
Roles	2.32	0.45	1.50	3.00	2.00	2.38	2.75
Affective responsiveness	2.10	0.42	1.33	2.83	1.83	2.00	2.50
Affective involvement	2.06	0.46	1.29	2.86	1.71	2.00	2.43
Behaviour control	1.64	0.37	1.11	2.11	1.22	1.67	2.00
General functioning	1.88	0.49	1.25	2.58	1.42	1.75	2.25
Total	**1.98**	**0.32**	**1.42**	**2.43**	**1.70**	**2.02**	**2.28**

Patient questionnaire - statistical analysis in preparation for comparisons across groups (n = 13)

Descriptive statistics for patients - Percentiles of FSS, FFS, FHI, and FAD

(a) FSS (n = 13)

Table 5

Frequency variables percentiles descriptive statistics

FSS subscales	Mean	Standard deviation	Minimum	Maximum	25th percentile	Median	75th percentile
Cohesion	37.69	29.01	1	94	16.00	34.00	59.50
Adaptability	58.23	30.16	19	94	22.00	58.23	88.00
Total	**43.00**	**29.65**	**1**	**91**	**17.50**	**40.00**	**68.50**

(b) FFS (n = 13)

Table 6

Frequency variable percentiles descriptive statistics

FFS subscales	Mean	Standard deviation	Minimum	Maximum	25th percentile	Median	75th percentile
Commitment	5.92	1.66	3	8	5.00	6.00	7.00
Appreciation	4.69	2.21	0	8	3.00	4.00	6.50
Time	5.31	1.80	2	8	3.50	6.00	6.50
Sense of purpose	5.77	2.24	1	8	4.50	6.00	7.50
Congruence	6.23	1.54	4	8	4.50	7.00	7.50
Communication	4.62	2.33	0	7	3.00	5.00	7.00
Role expectations	5.85	1.63	3	8	4.50	6.00	7.00
Coping 1	3.92	1.44	2	6	2.50	4.00	5.00
Coping 2	6.54	1.56	4	8	5.00	7.00	8.00
Problem solving	5.15	2.04	2	8	3.00	5.00	7.00
Positivism	5.69	1.93	1	8	5.00	6.00	7.00
Balance	5.00	1.78	1	8	4.00	5.00	6.00
Flexibility	6.00	1.78	3	8	4.50	6.00	8.00
Category scale: Family identity	**21.69**	**5.95**	**12**	**28**	**17.00**	**22.00**	**27.00**
Category scale: Information sharing	**10.46**	**3.64**	**3**	**14**	**7.50**	**11.00**	**14.00**
Category scale: Coping / Resource mobilization	**32.31**	**7.12**	**22**	**43**	**26.50**	**32.00**	**39.00**
Total	**64.46**	**14.73**	**37**	**84**	**54.00**	**66.00**	**77.00**

(c) FHI (n = 13)

Table 7

Frequency variable percentiles descriptive statistics

FHI subscales	Mean	Standard deviation	Minimum	Maximum	25th percentile	Median	75th percentile
Commitment	24.54	5.68	14.00	32.00	18.50	26.00	28.50
Challenge	14.38	3.40	9.00	18.00	11.00	15.00	17.50
Control	8.38	1.56	4.00	10.00	8.00	9.00	9.00
Confidence	11.77	3.54	6.00	16.00	8.50	13.00	14.00
Total	**59.08**	**11.92**	**39.00**	**74.00**	**48.00**	**62.00**	**69.50**

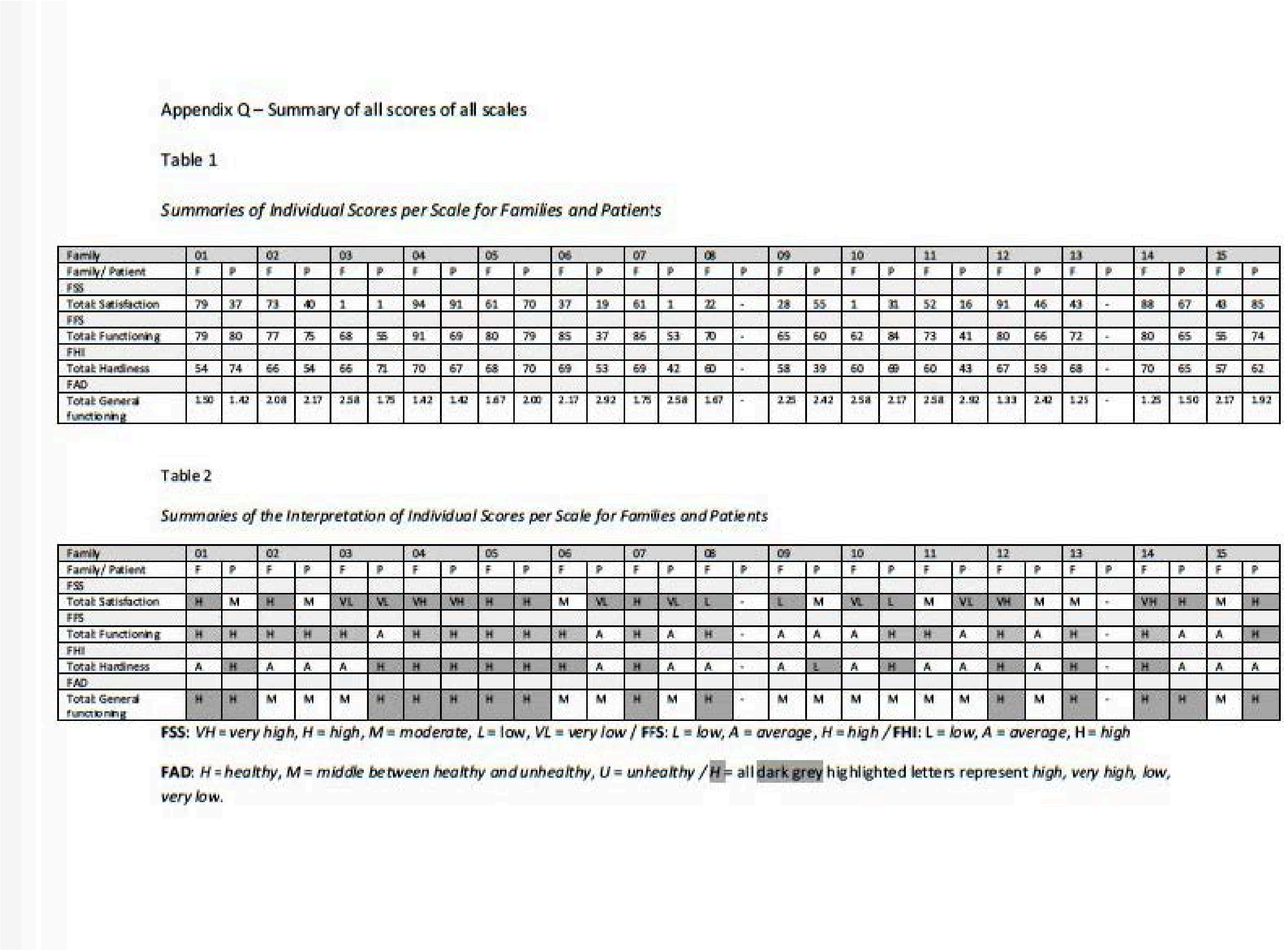
(d) FAD (n = 13)

Table 8

Frequency variable percentiles descriptive statistics

FAD subscales	Mean	Standard deviation	Minimum	Maximum	25th percentile	Median	75th percentile
Problem solving	2.23	0.64	1.40	3.20	1.60	2.20	2.90
Communication	2.38	0.57	1.67	3.83	2.00	2.17	2.75
Roles	2.55	0.32	2.13	3.25	2.38	2.50	2.81
Affective responsiveness	2.51	0.55	1.67	3.33	2.08	2.50	3.08
Affective involvement	2.35	0.33	1.71	2.86	2.14	2.29	2.57
Behavioural control	2.00	0.53	1.22	2.89	1.50	1.89	2.44
General functioning	2.12	0.52	1.42	2.92	1.63	2.17	2.50
Total	**2.28**	**0.36**	**1.81**	**2.89**	**1.97**	**2.26**	**2.61**

Appendix Q: Summary of All Scores of All Subscales



Appendix Q – Summary of all scores of all scales

Table 1

Summaries of Individual Scores per Scale for Families and Patients

Family	01		02		03		04		05		06		07		08		09		10		11		12		13		14		15	
Family/ Patient	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P
FSS																														
Total Satisfaction	79	37	73	40	1	1	94	91	61	70	37	19	61	1	22	-	28	55	1	31	52	16	91	46	43	-	88	67	43	85
FFS																														
Total Functioning	79	80	77	75	68	55	91	69	80	79	85	37	86	53	70	-	65	60	62	84	73	41	80	66	72	-	80	65	55	74
FHI																														
Total Hardiness	54	74	66	54	66	71	70	67	68	70	69	53	69	42	60	-	58	39	60	69	60	43	67	59	68	-	70	65	57	62
FAD																														
Total General functioning	1.50	1.42	2.08	2.17	2.58	1.75	1.42	1.42	1.67	2.00	2.17	2.92	1.75	2.58	1.67	-	2.25	2.42	2.58	2.17	2.58	2.92	1.33	2.42	1.25	-	1.25	1.50	2.17	1.92

Table 2

Summaries of the Interpretation of Individual Scores per Scale for Families and Patients

Family	01		02		03		04		05		06		07		08		09		10		11		12		13		14		15	
Family/ Patient	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P	F	P
FSS																														
Total Satisfaction	H	M	H	M	VL	VL	VH	VH	H	H	M	VL	H	VL	L	-	L	M	VL	L	M	VL	VH	M	M	-	VH	H	M	H
FFS																														
Total Functioning	H	H	H	H	H	A	H	H	H	H	H	A	H	A	H	-	A	A	A	H	H	A	H	A	H	-	H	A	A	H
FHI																														
Total Hardiness	A	H	A	A	A	H	H	H	H	H	H	A	H	A	A	-	A	L	A	H	A	A	H	A	H	-	H	A	A	A
FAD																														
Total General functioning	H	H	M	M	M	H	H	H	H	H	M	M	H	M	H	-	M	M	M	M	M	M	H	M	H	-	H	H	M	H

FSS: *VH = very high, H = high, M = moderate, L =* low, *VL = very low* / **FFS**: *L = low, A = average, H = high* / **FHI**: L = *low, A = average,* H = *high*

FAD: *H = healthy, M = middle between healthy and unhealthy, U = unhealthy* / *H* = all dark grey highlighted letters represent *high, very high, low, very low.*

From the information presented in Table 2 the following was observed: On the FSS, 7 families (in comparison with 4 patients) feel highly satisfied with their families. On the FFS, 12 families (in comparison with 5 patients) are functioning well. On the FHI, 5 families and 5 patients feel that their families have high hardiness. On the FAD, 8 families (in comparison with 6 patients) score high on general functioning.

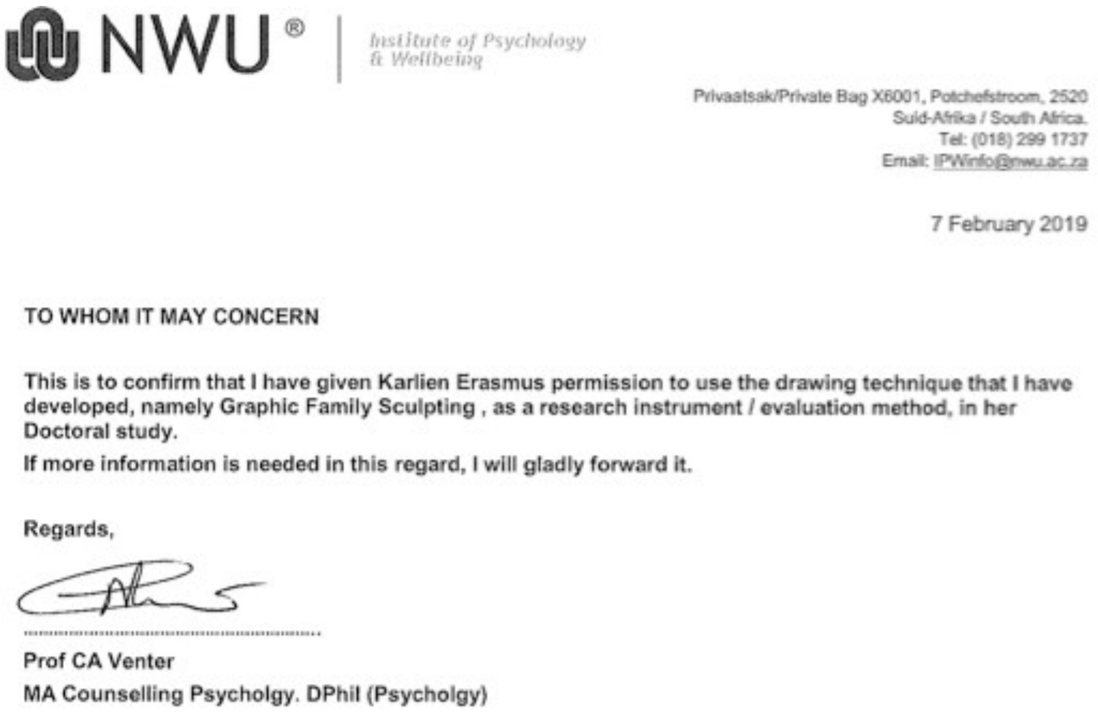
The following observations were made: Eight families experience the family process profiles (family satisfaction, family functioning, and hardiness) of their family to be better than what the patients experience it to be. Three patients experience the family process profiles (family satisfaction, family functioning, and hardiness) of their family to be better than what the family experience it to be. It seems that family members are more satisfied with how they experience their families than the satisfaction of the patients with their families. According to the family members, they experience their families to function better than what the patients experience the functioning of their families. The majority of patients experience the functioning of their families as not so good. Families and patients have mostly equal experience of the hardiness of their families. Overall, it seems that the family members experience the general functioning of the families to be better than what the experience of the patients is.

Appendix R: Summary of Thematic Analysis from Interviews with each family

Please note, the actual information pertaining to the above appendix was omitted due to personal and confidential information.

This relates to pages 271 to 287.

Appendix S: Permission to use GFS (Venter)



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7 February 2019

TO WHOM IT MAY CONCERN

This is to confirm that I have given Karlien Erasmus permission to use the drawing technique that I have developed, namely Graphic Family Sculpting , as a research instrument / evaluation method, in her Doctoral study.

If more information is needed in this regard, I will gladly forward it.

Regards,

Prof CA Venter
MA Counselling Psycholgy. DPhil (Psycholgy)

Appendix T: Coding and Co-coding of GFS

Please note, the actual information pertaining to the above appendix was omitted due to personal and confidential information.

This relates to pages 289 to 299.

Appendix U: Agreement to Act as Co-coder (Venter)

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& Wellbeing

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TO WHOM IT MAY CONCERN

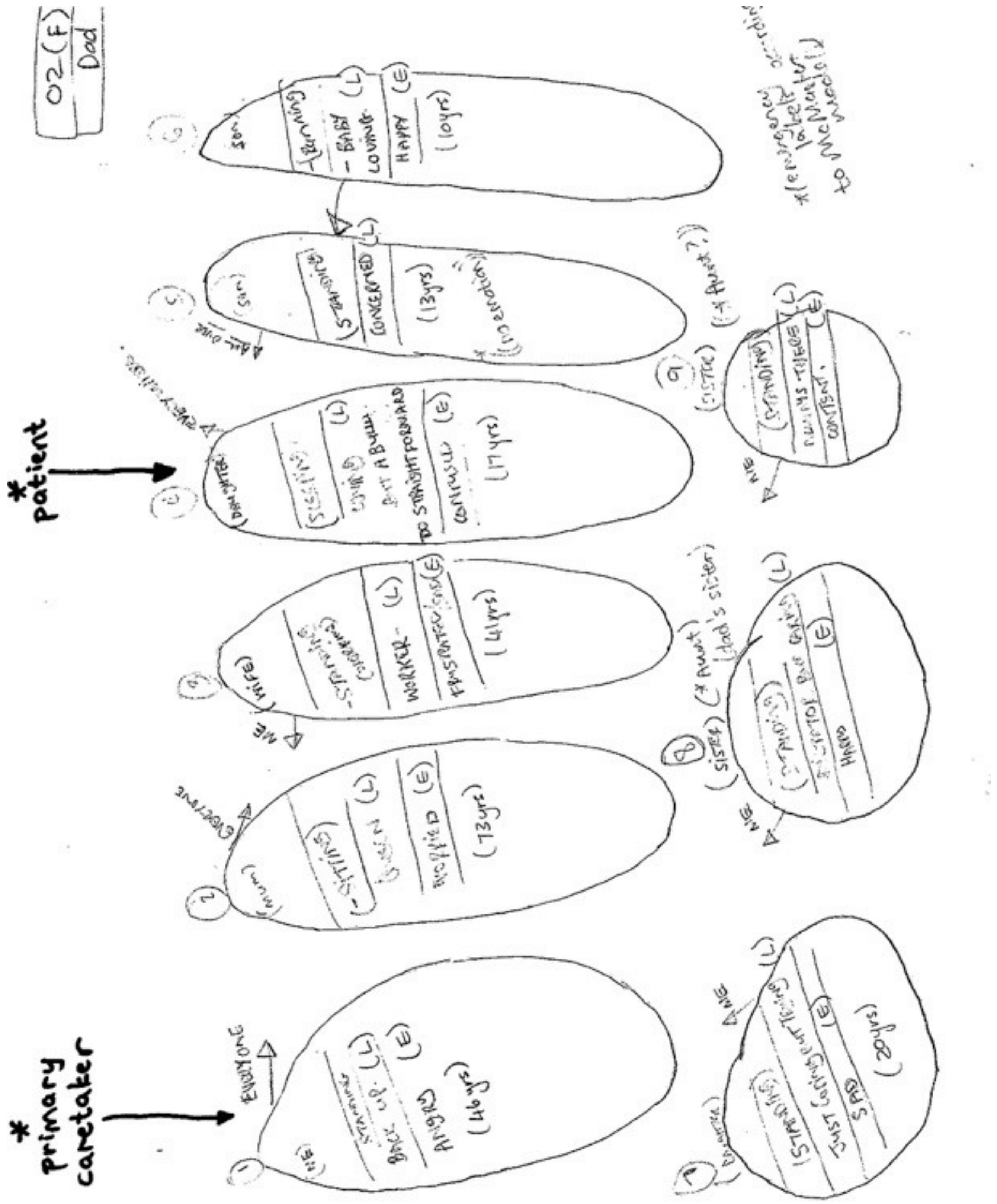
This is to confirm that I have agreed to be a co-coder of the Graphic Family Sculptings that was done by all the family members in Karlien Erasmus's Doctoral study. I also agreed to honor the confidentiality and ethical aspects of the research methodology.

If more information is needed in this regard, I will gladly forward it.

Regards,

Prof CA Venter
MA Counselling Psychology. DPhil (Psychology)

Appendix V1: Example of GFS



02LF
dad

①. THE ORDER OF OR SEQUENCE OF IMPORTANCE. TO ME.

②. WHAT BUSY BODIES THEY ARE.

③. WHO WUD THEY LOOK AFTR AND WHO WUD THEY LOOK TOO → FOR HELP.

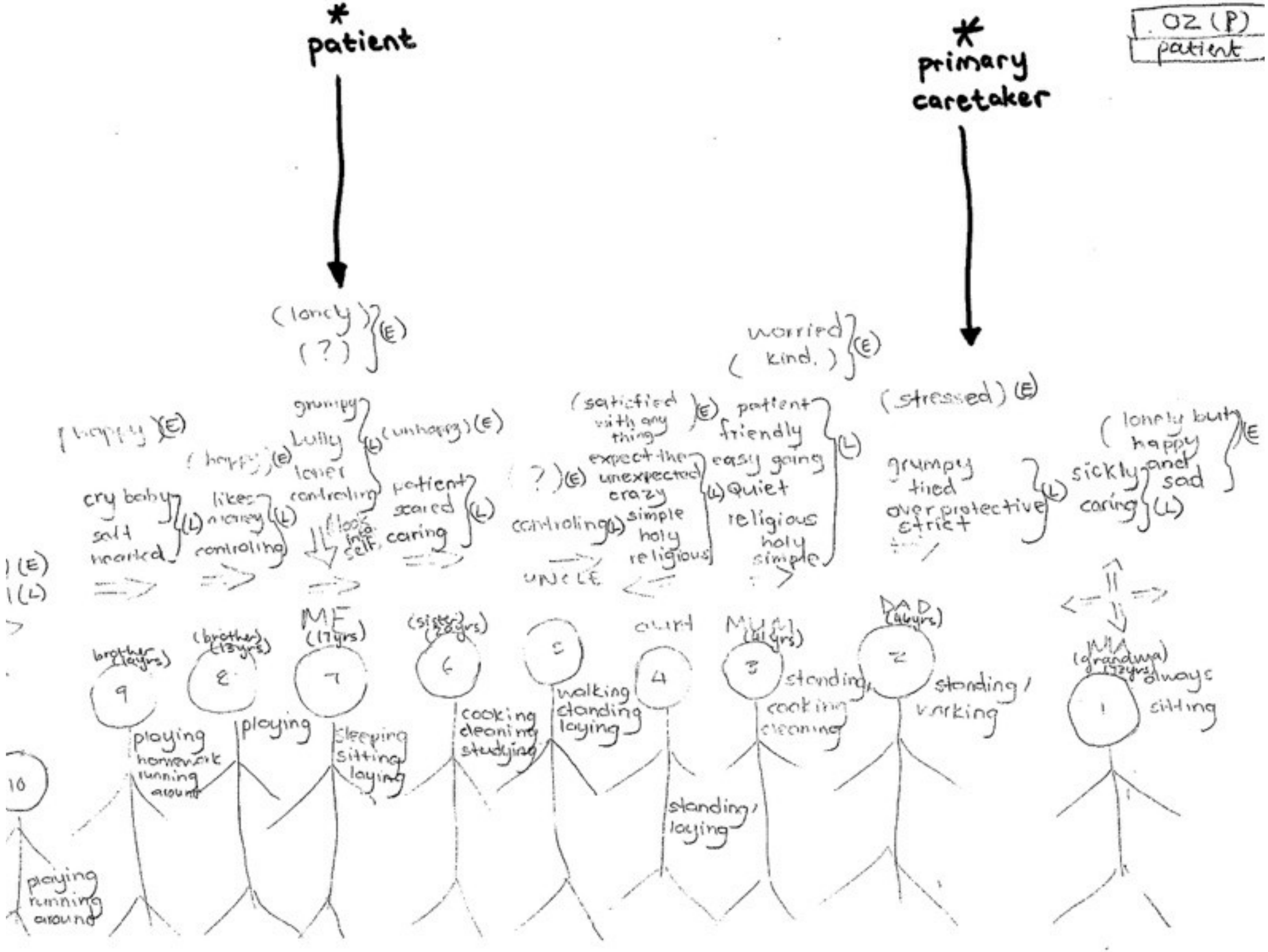
④. HOW I REALLY SEE THEM.

⑤. TOUGH 1 – NO NEW DISCOVERY JUST REALISATION.

⑥. NO.

⑦. YES.

⑧. YES.


OZ (P)
patient
* patient
* primary caretaker
(lonely) (?) (E)
(happy) (E)
cry baby salt hearted (L)
brother (14yrs)
9
playing homework running around
10
playing running around
(happy) (E)
likes money controling (L)
(brother) (13yrs)
8
playing
grumpy bully loner controling (L)
(unhappy) (E)
(loos into self)
ME (17yrs)
7
sleeping sitting laying
patient scared caring (L)
(sister) (20yrs)
6
cooking cleaning studying
(?) (E)
controling (L)
UNCLE
5
walking standing laying
(satisfied with any thing) (E)
expect the unexpected crazy simple holy religious (L)
aunt
4
standing / laying
worried (kind.) (E)
patient friendly easy going quiet religious holy simple (L)
MUM (41yrs)
3
standing cooking cleaning
(stressed) (E)
grumpy tired over protective strict (L)
DAD (46yrs)
2
standing / working
(lonely but happy and sad) (E)
sickly caring (L)
MA (grandma) (72yrs)
1
always sitting
(E)
(L)

O2(P)
patient

1 Generous, caring but crazy

2 Hard-life

3 Everyone trying to plz someone
= everyone looks up to my father
= scared of him

4 Me and dad are similar and aunt and mum also

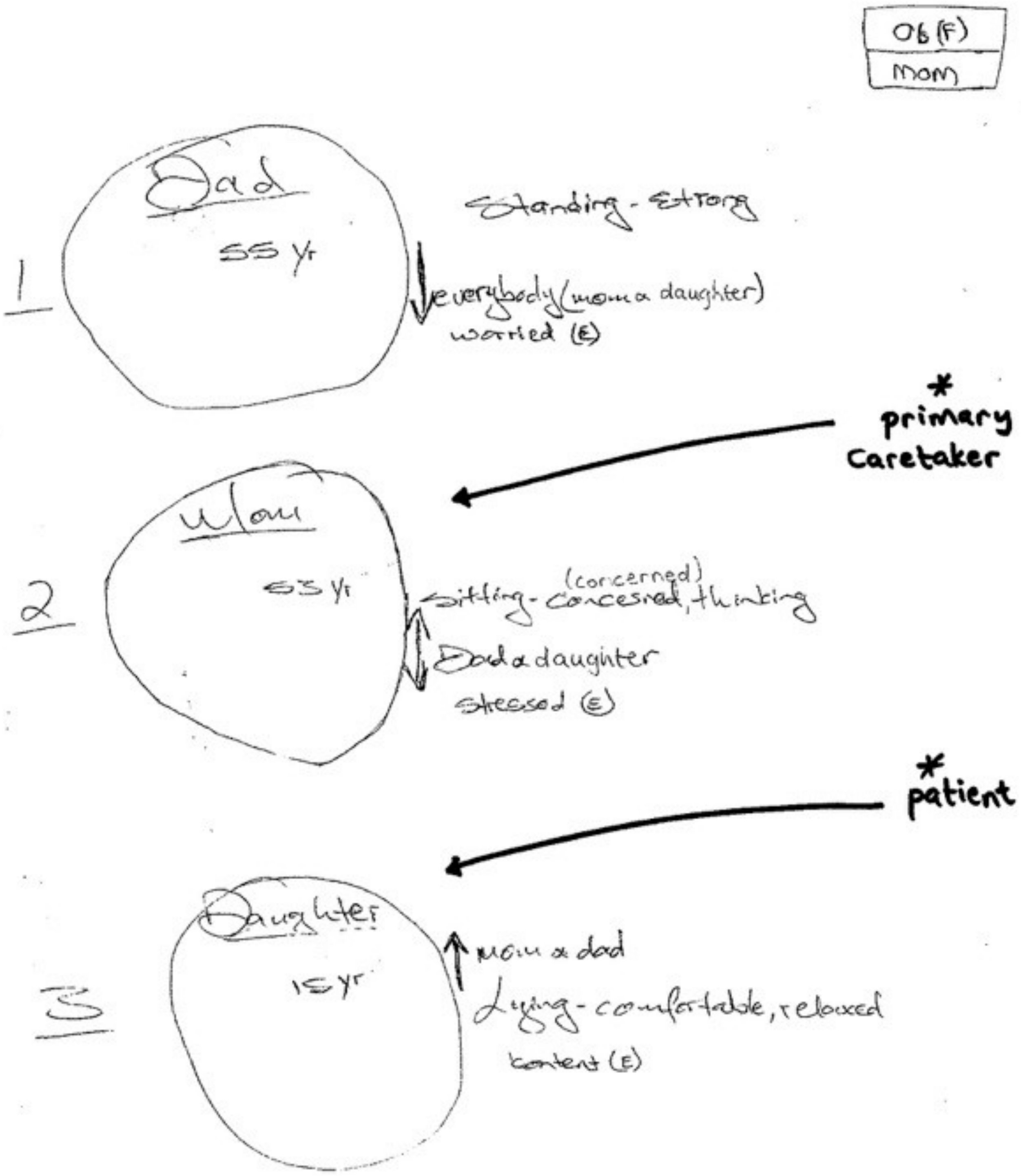
5 only happy when we together

6 NO

7 YES

8 No, but got me thinking

Appendix V2: Example of GFS



06(F)
mom

① Dad the strong provider, mother nurture, daughter to protect. We are all equal special individuals.

② Dad special, in control, I am the one to make things 'work' see all is fine. Daughter in a relaxed. carefree zone.

③ Respect for each other, acknowledge the roll each one plays in the family

④ ① caring (Lion) (2) Really caring, Loving provider, protector
② Strict (Lioness) (2) Can be controlling and sometimes unfair
③ horse (elegant) (2) Good natured, soft but strong when needed

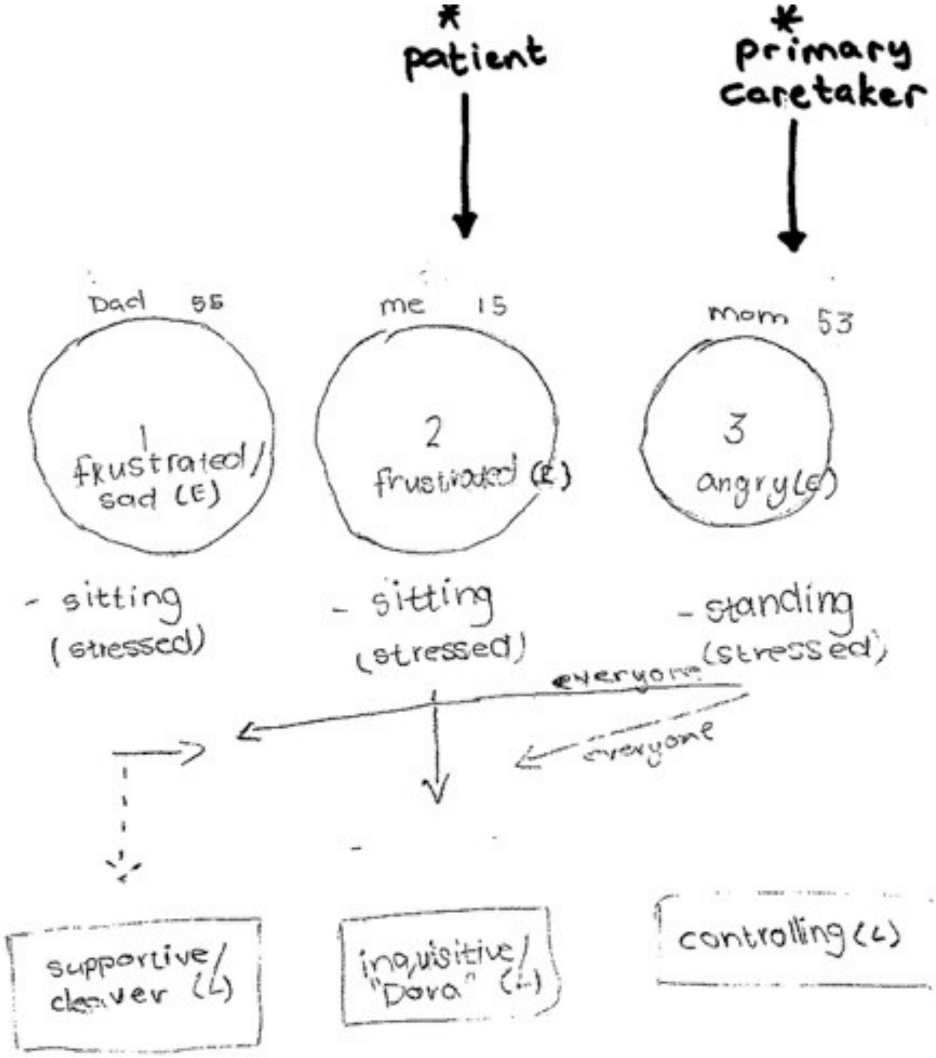
⑤ We are under pressure/stress. We need to work on/make plans to be closer to Dad.
We are a happy family doing the best we can, although challenges.

⑥ Yes

⑦ Yes

⑧ Yes

06(P)
patient


* patient
* primary caretaker
Dad 55
me 15
mom 53
1 frustrated/ sad (E)
2 frustrated (E)
3 angry (E)
- sitting (stressed)
- sitting (stressed)
- standing (stressed)
everyone
everyone
supportive/ clever (L)
inquisitive/ "Dora" (L)
controlling (L)

Ob(P)
patient

1) - Dad is important in my life
   - Role modle

2) Represents situations, arguing and heirachy change; sitting = afraid

3) Nothing new, mother looking and shouting, want to be in control, dad and I ommitting because all we can do to stop shouting

4) Very Clear who controlls family and makes Life difficult (mother), makes dad look bad; call him useless and a procrastinator. Says I am ungreatfull and does not allow me to explore or do what I want. Dad loves & supports me,

"Dora" - name friends gave me because knowledgable & love exploring outdoors & helping peaple.

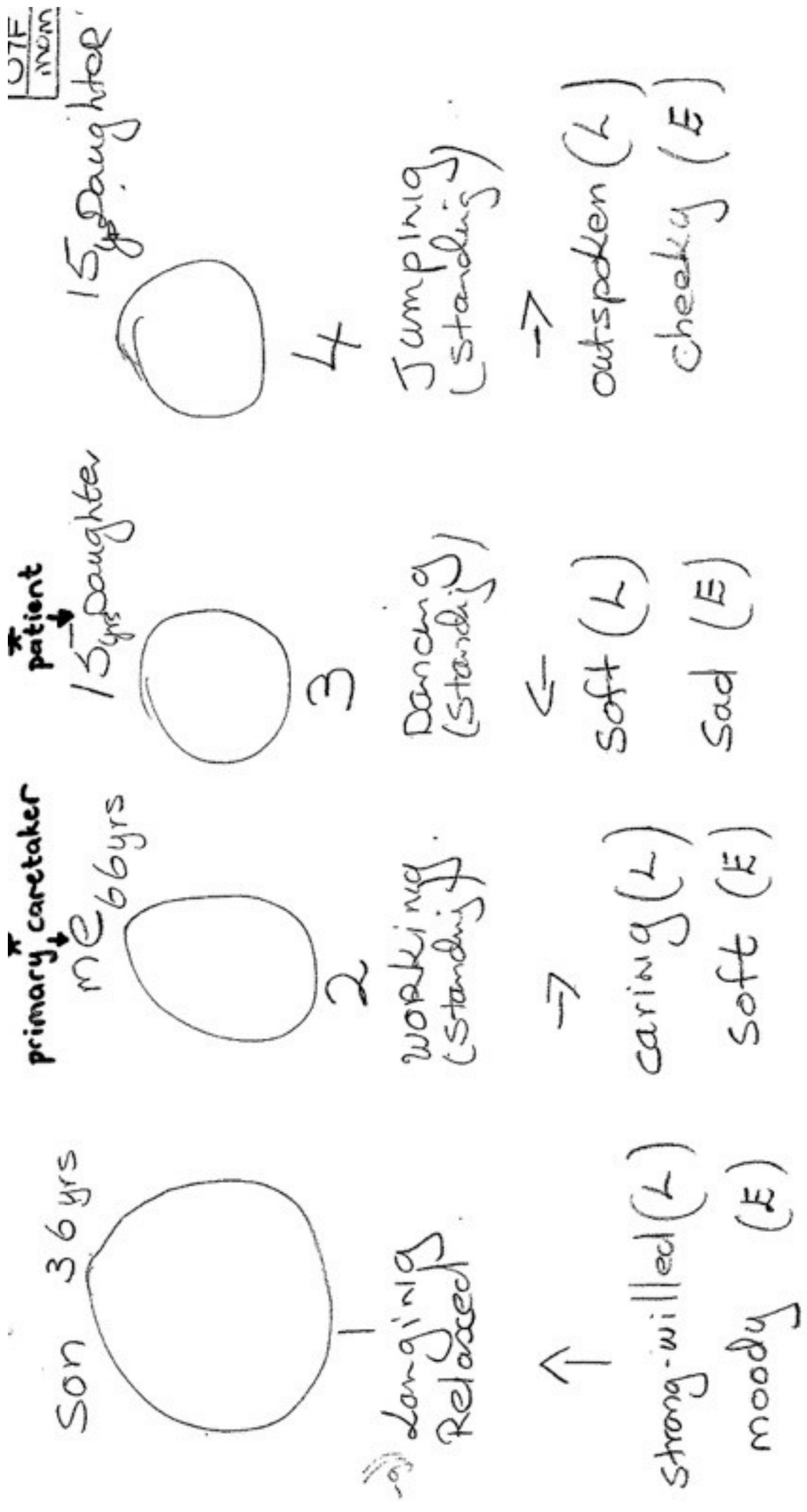
5) Nothing new. Disfunctional, unhappy family because of one person.

6) Yes

7) NO

8) NO

Appendix V3: Example of GFS



O7F
mom

1. That my son is important part of the family.

2. That some members work harda than others.

3 My son is worris about himself I am worried about daughters.

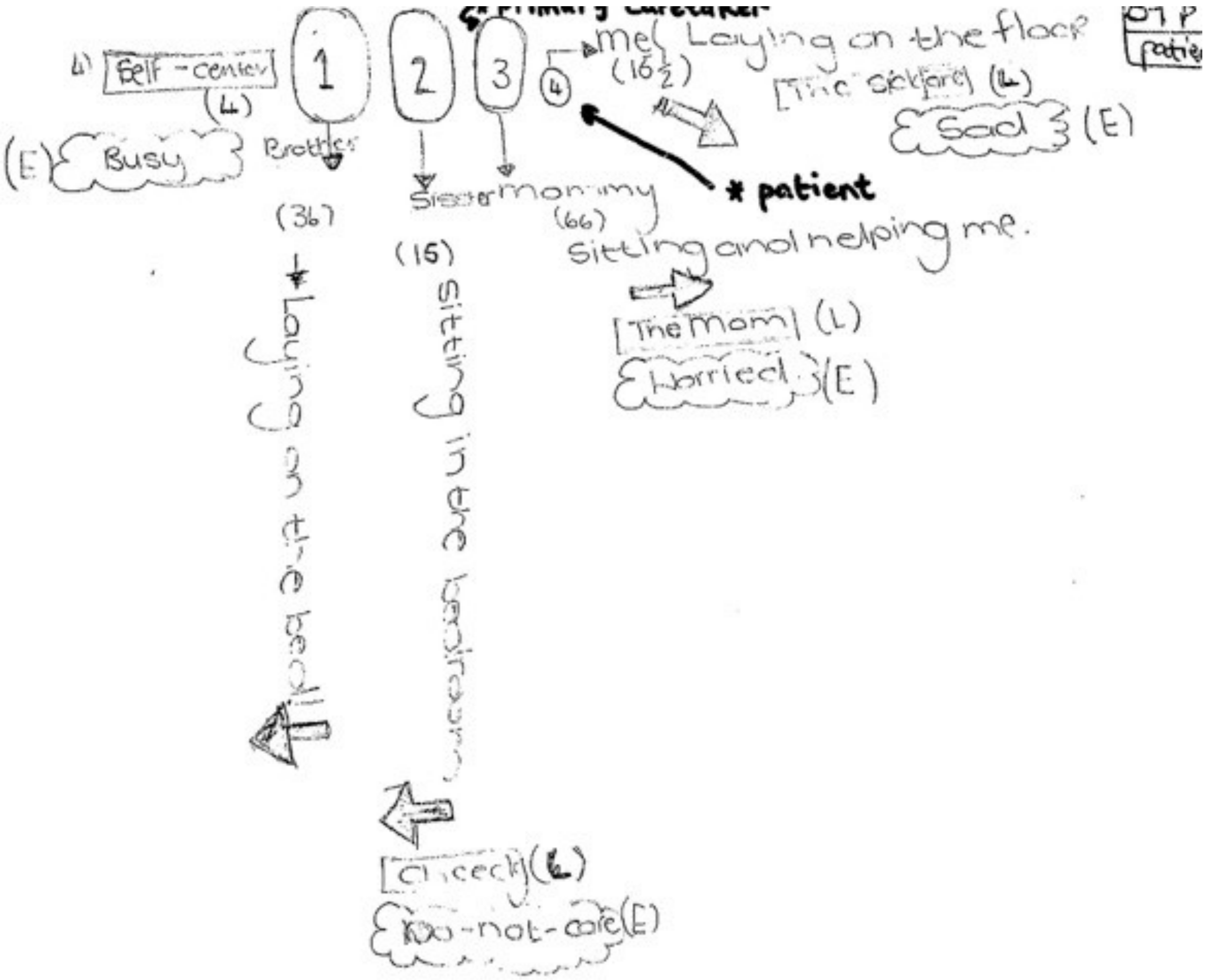
4 That we are all differant!.

5 No Nothing New.

6 yes

7 yes

8 NO


* Primary caretaker
4) Self - center
(L)
(E) Busy
1
Brother
(36)
Laying on the bed!!
2
Sister
(15)
Sitting in the bedroom
Cheeky (L)
Do-not-care (E)
3
mommy
(66)
Sitting and helping me.
The mom (L)
Worried (E)
4
me
(16½)
Laying on the floor
The sick one (L)
Sad (E)
* patient
patie

07 P
patient

(1) [illegible] I feel very small in the family
(2) Mommy is always helping me
(3) Mommy is always locking after me,
brother and sister don't looking after me
④ I feel always sick
⑤ Brother is one-side
⑥ No
⑦ Yes
⑧ Yes