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Experiences of adolescents living with epilepsy in South Africa

by

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Abstract

Several studies have highlighted the perspectives and insights of healthcare workers and caregivers involved in ensuring the well-being of adolescents with epilepsy. Research from the perspective of the adolescent living with epilepsy is, however, lacking, especially in the South African context. This qualitative study therefore aimed at exploring and understanding the experiences of adolescents living with epilepsy in South Africa, within an interpretative phenomenological framework. Semi-structured interviews were conducted online via Zoom with three adolescents diagnosed and living with epilepsy. The data was analysed using Interpretative Phenomenological Analysis (IPA) which allowed for the emergence of prominent themes and subordinate themes. The four main themes that emerged were: *mental health challenges; cognitive challenges; treatment, support, and coping; and emotional insights.* The findings of the study indicated that the participants experienced cognitive challenges such as memory problems which impaired their daily functioning and had an influence on academic performance. The findings further revealed that the participants experienced psychological challenges, such as anxiety, depression, and epilepsy-related fears. The experiences of these adolescents revealed similarities and unique differences in the many facets of their lives, from access to medical treatment, social and cognitive challenges, emotional and personal development, and support systems and how living with epilepsy shaped these experiences. These lived experiences in turn influenced the emotions, insights, and ambitions of these adolescents. The findings of this study provide insight into identifying and understanding the needs, the challenges, and the world view of these young people living with epilepsy in South Africa. The findings further highlight that cultural context, background, and personal factors may shape the experiences of these young people living with epilepsy; thus, a recommendation for future research in diverse cultural contexts is made by the researcher.

Key words: Epilepsy; Adolescent; Psychological; Social; Cognitive; South Africa; Interpretative Phenomenological Analysis

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Declaration

I, Zahrah Hassim Moosa, 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.

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Sign Date

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CHAPTER 1: INTRODUCTION

In this chapter the background, rationale and justification for the study will be discussed. The research problem and research question, aim, and objectives of the study will be identified. Significant terms will be defined, and the research design will be discussed. Lastly, the layout of the thesis will be broken down into chapters and each chapter will be described.

1.1 Description of research

Epilepsy is a brain disorder characterised by neurobiological, cognitive, psychological, and social implications (Fisher et al., 2005). The fact that social, psychological, and cognitive consequences are part of this definition suggests that the implications of this disorder are far greater than just neurological sequelae. Epilepsy often occurs comorbidly with other physical and psychological conditions (Kessler et al., 2012). Psychological conditions such as mood disorders, anxiety disorders, cognitive impairment, social cognition disorder, schizophrenia, autism, and psychosis are common comorbidities in persons with epilepsy (Rodriguez et al., 2022). Metabolic, respiratory, and cardiovascular diseases are also known physical comorbidities of epilepsy (Paudel et al., 2018). Epilepsy presents with a prevalence rate of 5,5 in 1000 and is seen as a common chronic illness in children and adolescents (Pauschek et al., 2016), especially in low to middle-income countries (de Boer, 2010) where over 80% of persons with epilepsy reside (Anguzu et al., 2020). Significant advancements have been made in the past 30 years with regards to the treatment of different types of seizures and understanding the nature of epilepsy (Ghosh, 2021). Owing to negative public attitudes, political neglect, social stigma, and lack of resources these advancements have not been fully implemented, especially in developing countries (Owolabi et al., 2020; Reynolds, 2001). The epilepsy treatment gap in Sub-Saharan African countries, including South Africa, is about 69% (Owolabi et al., 2020). The current researcher therefore identified the need for this type of research in a developing country such as South Africa.

Adolescence is an especially important stage in the life of a child with epilepsy, as it marks the point of transition from childhood epilepsy to adult epilepsy. This transition is complicated by the shift from paediatric care and treatment to adult care and treatment. Children and adolescents diagnosed with epilepsy tend to face more daily difficulties and tend to have poorer social skills (Pauschek et al., 2016). In South Africa, there is a lack of availability of appropriate special needs education, treatment centres, a prevailing misconception of epilepsy as a disease that has a spiritual cause, as well as limited resources and access to specialised treatments (Williams et al., 2015). Adolescents diagnosed with epilepsy face numerous challenges in managing the disorder in the context of limited resources and extensive cost. For instance, treatment centres may be few and located far from the community, requiring patients to travel considerable distances. These adolescents do not only struggle with managing the disorder, but also face emotional and social challenges as the stigma attached to the diagnosis has been shown to exacerbate social isolation, exclusion, and lack of community support (Williams et al., 2015).

The current researcher based this study on the experiences of adolescents living with this neurological disorder. The topic is one of personal affiliation to the researcher who has witnessed the manifestation of the disorder in close quarters. The researcher is therefore aware of the importance of being reflexive and has kept a reflective diary throughout the research process in which the researcher's possible biases, personal beliefs and values are reflected on.

In this study, the experiences of three adolescents living with epilepsy were explored and analysed. The participants were recruited through the organisation Epilepsy SA and each differed in their cultural and socioeconomic backgrounds. The communication with the adolescents also involved communication with the parents/guardians of these adolescents who highlighted to the researcher the unique conditions of caring for an adolescent living with epilepsy.

1.2 Research question

The current study aimed to obtain an understanding of the experiences of adolescents living with epilepsy in South Africa. Using a phenomenological approach, a meaningful account of these experiences could be collected and analysed. The research question is: What are the experiences of adolescents living with epilepsy in South Africa?

1.3 Justification, aims, and objectives

The justification for the current study is discussed in the following subsections. The aim and objectives of the study are also outlined.

1.3.1 Justification of study

Numerous studies highlight the perspectives of healthcare workers and parents who deal with children with epilepsy (Harden et al., 2021; Nabbout et al., 2020; Pauschek et al., 2016; Puka et al., 2018;). There is, however, limited research from the perspective of the child or adolescent living with epilepsy (Pauschek et al., 2016). There is a clear need for more qualitative research undertaken from the perspective of the adolescent living with epilepsy (Harden, 2021). A study by Keikelame and Swartz (2016), also highlighted this lack of qualitative research regarding the experience of living with epilepsy in South Africa.

The prevalence of epilepsy in 2015 was estimated to be around 69 million people worldwide (Gilani et al., 2015), with 13 million of these people situated in Africa. In South Africa, it is estimated that 1 in every 100 persons lives with epilepsy (Keikelame & Swartz, 2013). Furthermore, epilepsy is known to be one of the most common neurological disorders in children with an incidence rate of 40 to 50 per 100 000 children (Wirrell et al., 2011). Adolescents with epilepsy must cope with their condition and treatment as well as with the challenges of a regular adolescent, such as striving for autonomy and establishing themselves as young adults (Marin, 2005; Nordli, 2001). This emphasised the need for more research and a better understanding of the experience in children and adolescents.

1.3.2 Aim and research objectives of the study

The aim of the current study was to explore the experiences of adolescents living with epilepsy in South Africa. The objectives of the study were to explore from the adolescent's perspective the social, psychological, and cognitive implications of living with epilepsy, to explore the world view of an adolescent with epilepsy, and to explore and describe the challenges faced by adolescents living with epilepsy.

1.4 Theoretical framework

This study made use of phenomenology as the theoretical framework as well as the methodology. Phenomenology is defined broadly as the study of lived experiences (Laverty, 2003). The focus was on in-depth descriptions and finding meaning and insight into lived experiences of individuals. Edmund Husserl, the father of phenomenology, viewed the human being as a living, thinking being, whose context could not be ignored. He emphasised that the most authentic research comes directly from the lived experiences of human beings and that all stimuli external to the consciousness of the person should be ignored (Groenewald, 2004). According to the hermeneutic phenomenological research paradigm, reality is a construct that depends on the individual and their context and is constructed by the person; hence multiple realities are said to exist (Kafle, 2013).

1.5 Research design and methodology

The researcher employed a qualitative approach in this study. Interpretative Phenomenological Analysis (IPA) was used as the research design. Data was collected by means of in-depth, open-ended interviews with the aim of gaining insight into the lived experiences of the participants and allowing for flexibility in exploration. The interviews were conducted online as stipulated by Covid-19 protocol at the time of data collection.

Purposive sampling was employed. Adolescents between the ages of 13 to 19 who had been diagnosed with epilepsy a minimum of one year before, were included in the study. The participants were recruited by and referred to the researcher by the social workers at Epilepsy SA. Data analysis was conducted according to the IPA guidelines provided by Pietkiewicz and Smith (2014). Themes from the individual interview scripts, and between different cases, were identified and explored. Interpretations were based on the data collected. The researcher played a reflexive, interpretive, and collaborative role in the analysis, as per IPA guidelines (Pietkiewicz & Smith, 2014).

1.6 Definition of concepts

Adolescence is a development stage identified as the transitional phase between childhood and adulthood. It is marked by biological growth, social development, and several changes attributed to the occurrence of puberty (Sawyer et al., 2018). Adolescence is further defined as a stage in life during which social and psychological development take place and emphasis is greatly placed on peer support and formation of self-identity (Wilde & Haslam, 1996). For the purposes of this study, the term adolescent refers to an individual within the range from 13 to 19 years of age.

Epilepsy is a brain disorder defined medically by the occurrence of seizures. The disorder is also defined and identified by the "neurobiological, cognitive, psychological, and social consequences of this disorder," (Fisher et al., 2014, p. 476). Epilepsy is the most common neurological disorder and is prevalent across all ages, classes, and races (Spiciarich et al., 2019). The World Health Organisation (WHO, 2022) defines epilepsy as a chronic disorder that is characterised by recurrent seizures. Recurrent seizures are brief periods of involuntary movement of a part of the body or the entire body. Seizures may be accompanied by loss of consciousness and loss of bladder and/or bowel control (WHO, 2022).

1.7 Structure of thesis

- **Chapter 1: Introduction**

In the introduction chapter, the background and rationale behind the study are introduced. The research question, aims and objectives are outlined. An overview of the theoretical framework and the research design are discussed. The definitions of significant concepts are explained, and the layout of the thesis is also presented.

- **Chapter 2: Literature review**

In this chapter, existing literature on epilepsy, adolescents, the psychological impacts of epilepsy, the history of epilepsy in a South African context, treatment, family studies, studies undertaken on the experiences around epilepsy and the effects on the youth in general are reviewed and discussed. The gap is identified for further research in the field and the significance thereof.

- **Chapter 3: Theoretical framework**

In this chapter, the theoretical framework adopted in this study is explored and explained in relation to the study topic at hand. The researcher employs a phenomenological approach to understand the experience of adolescents from their perspective.

- **Chapter 4: Methodology**

In the methodology chapter, the researcher describes the chosen methodology along with its procedures and steps to be conducted.

- **Chapter 5: Findings**

In this chapter, the qualitative results of data analysis are explored in depth.

- **Chapter 6: Findings**

The findings are discussed in relation to existing literature and explored further. Suggestions for further research are also shared. The limitations of the study are explored and reflected on by the researcher in this chapter. The personal reflections of the researcher are explored.

1.8 Conclusion

The aim of this study was to explore the experiences of these adolescents living with epilepsy within the South African context. In Chapter 1, the research process was explored, and definitions of significant concepts as well as the structure of the contents of the thesis were outlined. In Chapter 2 the literature of the study subject is discussed.

CHAPTER 2: LITERATURE REVIEW

This literature review provides background information and a foundation through a review and analysis of existing research studies related to the topic being investigated in the current study. The chapter defines epilepsy as a disorder and presents relevant research conducted on understanding the experience of living with this disorder, especially in a South African context. The chapter goes on to define adolescence and presents existing literature on adolescents' experiences of living with epilepsy.

2.1 Epilepsy

Epilepsy is a common disorder of the brain and is prevalent across all ages, classes, and races (Reynolds, 2001; Spiciarich et al., 2019). It can occur in any person at any point in life (Sheridan et al., 2016). Predominantly, epilepsy has a childhood onset, and therefore is more prevalent in children and adolescents (Kirabira et al., 2020; Riechmann et al., 2019). The word "epilepsy" is derived from a Greek word, *epilambaneim*, which means to seize or to take (Marin, 2005). Epilepsy is a chronic disease of the central nervous system. There are many underlying causal mechanisms that result in epilepsy, such as brain injuries, infections, malnutrition, and so forth. Most of these aetiological factors are more common in poorer areas thus highlighting that poverty is a risk factor in developing preventable epilepsy (Anguzu et al., 2020). The actual cause in at least 50% of worldwide cases is, however, still unknown (Beghi et al., 2019; Deegbe et al., 2019). Some causes of secondary epilepsy – epilepsy as a result of another condition – include stroke, infectious diseases, inflammatory disorders, brain tumours, traumatic brain injuries, neurodegenerative disorders, and congenital anomalies (Beghi et al., 2019). The pathognomonic symptom of epilepsy is known to be the occurrence of unprovoked epileptic seizures (Wirrell et al., 2011). The consequences of these recurrent and debilitating seizures regarding both physical and psychological factors make epilepsy a burdensome neurological disorder (Beghi et al., 2019).

2.1.1 Seizures

A seizure is an episodic disturbance of movement, feeling, or consciousness caused by a sudden, inappropriate, excessive electrical activity in the cerebral cortex (Brodie & French, 2000). The normal electrical activity within the brain is disrupted and this results in a seizure. The symptoms include uncontrolled musculoskeletal movements as well as a loss of consciousness.

The person is often unaware of what is happening to them during a seizure, due to this loss of consciousness (Deegbe et al., 2019).

These seizures may occur suddenly and be quite debilitating, leaving the victim afraid to leave their home in fear of experiencing a seizure outside (de Boer et al., 2008; Sheridan et al., 2016). It also inhibits their willingness to interact with others, seek outside employment, and engage in day-to-day activities. Having seizures in public may be experienced as humiliating, indecent and can result in lowered self-esteem (Deegbe et al., 2019). Though severe, the frequency of neurological manifestations can be managed with anti-epileptic drugs or AEDs (de Boer et al., 2008). Anti-epileptic drug treatments have been successful in rendering up to 70% of patients seizure-free (Beghi et al., 2019).

Unlike people with any other chronic disease, people with epilepsy are only partially aware of the major manifestations of the disorder. The biggest consequence, seizures, usually results in a loss of consciousness as well as amnesia (Meißner et al., 2019). Many people only experience their seizures through the account of a bystander and cannot themselves recall the incident. Seizures occur quite spontaneously and can therefore be experienced as a threat to one's physical well-being as well as a constant fear of a seizure being an embarrassing occurrence in public. This fear is essentially a fear of losing control and can have an adverse effect on quality of life (Meißner et al., 2019). According to Beghi et al. (2019), despite an overall decrease in degree burden, epilepsy still contributes to disability and mortality. Seizure severity is reported to be a contributing factor to lowered quality of life. Furthermore, research shows that achieving seizure control at an early stage, especially in younger persons with epilepsy, improves quality of life (Riechmann et al., 2019). A study conducted by Siqueira et al. (2014) reported that adolescents who were considered seizure-free, who had some level of seizure control, and who had fewer instances of experiencing seizures in public, scored higher on the quality-of-life scales.

2.1.1.1 Types of Seizures

The type of seizure depends on multiple factors: patient age, general health, aetiology, and the affected area of the brain (Marin, 2005). There are two types of seizures, namely generalised and focal (partial) seizures. Focal seizures occur only in one area in the brain, while generalised seizures involve activity throughout both hemispheres of the brain (Marin, 2005; Ryan & Räisänen, 2012). There are several types of generalised seizures. Absence seizures last only a few seconds and are characterised by staring spells in which an individual stops what they are doing and stares ahead either keeping completely still throughout the seizure or making chewing sounds with the mouth. This may occur with or without automatisms. An automatism is a behaviour performed without conscious control. Tonic seizures cause stiffness and rigidity to the body, and clonic seizures cause jerking movements of the muscles of the body. Tonic-clonic seizures manifest by first causing stiffness in the body followed by a short cry through the vocal-chords, and then a repeated pattern of jerking of the body. Tonic-clonic seizures also involve a loss of consciousness, and sometimes, a lack of bladder control. Myoclonic seizures cause a quick jerk or twitching of the upper body, arms or legs. Akinetic seizures cause a person to immediately drop to the ground and recover instantly. Atonic seizures cause a loss of muscle tone causing the person to limp for a long time or drop to the ground and these may last up to a few minutes (Marin, 2005; Ryan & Räisänen, 2012).

Focal seizures can either be simple partial or complex partial seizures (Ryan & Räisänen, 2012). In simple partial seizures, the person remains conscious, but may experience some strange feeling, movement, or sensation. A complex partial seizure is similar, except that there is a change or loss in consciousness (Marin, 2005). These seizures manifest in symptoms such as involuntary movements, difficulty speaking, feelings of déjà vu, feeling scared, or even sick. Before the seizure, a person may experience an aura or warning that a seizure is about to occur. This pre-seizure feeling is a type of focal seizure. Focal seizures can eventually manifest in generalised seizures (Marin, 2005; Ryan & Räisänen, 2012).

2.1.2 Physical and psychological comorbidities and consequences

Epilepsy is highly comorbid with other physical and psychological disorders; thus, further limiting the functional ability, employment opportunities, and social interactions of the patient (Kessler et al., 2012). The physical comorbidities include stroke, asthma, hearing impairments, visual impairments, and digestive disorders.

Anxiety and depression are common comorbidities of epilepsy and occur in 20% to 55% of all cases of epilepsy (Kerr, 2012; Tolchin et al., 2020; Verma et al., 2015; Yeni et al., 2018). The manifestations of these conditions in people with epilepsy include fatigue, irritability, poor quality of life, poor medication adherence, and increased risk of suicidal behaviour (Tolchin et al., 2020. According to research done by Mula (2017), epilepsy today presents as a complex psychiatric disorder as well as a neurological disorder, as there seems to be an overlapping relationship between epilepsy and depression, thus introducing a 21st-century problem of a double stigma in patients with epilepsy. The neurobiological links between epilepsy and depressive disorders is not fully understood. What is known is that depression and temporal lobe epilepsy both cause disruption in the same brain circuits. Low serotonin levels are also a key characteristic of mood disorders and evidence suggests that this is the case in epilepsy as well. Further studies are still needed to fully understand this link in underlying neurobiological mechanisms (Mula, 2017).

Depression is in fact the most common comorbidity associated with epilepsy and is more prevalent in epilepsy than any other chronic disorder (Yıldırım et al., 2018). The relationship between seizures and depression is bidirectional; meaning that people with epilepsy are more at risk of developing depression and depressed persons are at risk for new-onset epilepsy (Danzer, 2012). This highlights the importance of depression management together with seizure treatment (Kerr, 2012). The risk of depression is especially high in patients with intellectual disability (Kerr, 2012). Cognitive impairment is a common comorbidity of epilepsy and is a side effect of using anti-epileptic drugs (AEDs), but also caused by ongoing seizures (Baker et al., 2008).

Memory, concentration, and psychomotor speed are some of the cognitive impairments common in epilepsy, and this in turn could increase the likelihood of physical injuries (Kerr, 2012). Loss of control, overprotectiveness by family, lack of self-esteem, failure at work and education contribute to the depression and negative attitudes (Yeni et al., 2018). Seizures have physical consequences such as severe injuries including bruises, sprains, burns, and fractures. Patients with epilepsy report two to six times more bone fractures than the general population due to seizure-related injury (Kessler et al., 2012).

2.1.3 Psychosocial and emotional impact of epilepsy

Epilepsy is deemed a medical diagnosis and social label. As a condition, it is medically treatable. Its psychosocial consequences are, however, far-reaching (Mpoe et al., 2017). Epilepsy is described as a disorder that places a great burden on the self, on society, and on the caregiver. Epilepsy weighs on many life aspects, from mobility, career choices, being self-sufficient, injuries due to epilepsy-related accidents, forming relationships, family planning, safety and security, financial stability, and so forth. All these life spheres contribute to an overall drop in quality of life of the individual with epilepsy (Riechmann et al., 2019).

Epilepsy is unique in the challenges that it poses for a person. One challenge is its characteristic of being potentially invisible. People with epilepsy do not bare a visible impairment and hence it is not apparent in social situations, apart from having a seizure in public. This concealment enables the person living with epilepsy to be selective in whom they choose to disclose their disorder to (Eklund & Sivberg, 2003). This invisibility and unpredictability of seizures can be very confusing for people, especially children with epilepsy, and can leave them feeling vulnerable when communicating their disorder to peers, teachers, and family members. This, and the societal stigma attached to the disorder, often leaves a silence around epilepsy. This silence may have serious implications for the physical and psychosocial well-being of the person living with epilepsy. The lack of a supportive system could impair the ability to cope with this disorder (O'Toole et al., 2016).

The psychosocial impact of childhood epilepsy is reported to be more critical than the actual seizures (Baker et al., 2005; O'Toole et al., 2016). A study by Baker et al. (2005) reported that adolescents with epilepsy displayed higher levels of depression and social anxiety than adolescents who do not have epilepsy. The study also showed that high seizure frequency was significantly associated with low self-esteem. Tonic-clonic seizures were found to be specifically associated with high levels of depression. It was also found that adolescents who had low levels of knowledge about epilepsy experienced lower self-esteem, higher depression levels, and higher levels of social anxiety. The study showed that adolescents with high levels of knowledge about their condition were less likely to report psychosocial issues and less likely to be depressed. One reason why an adolescent may have low levels of knowledge about epilepsy is the desire to suppress the existence of their disorder out of fear of being stigmatised (Baker et al., 2005).

Emotions are both constructed and mediated by the society we live in. How we make sense of emotions is a complex process that involves the interaction of social, cultural, psychological, and physical factors. The emotion of fear is persistent in a world where chronic illnesses, such as epilepsy, are becoming more prominent. The fear of developing a chronic illness is also evident (Ryan & Räisänen, 2012). Epilepsy is unique in its relationship with emotions. Emotions are said to rise before, during and after seizures. A range of emotional stimuli and stress can trigger epileptic seizures (Amlerova et al., 2014).

In a study conducted by Ryan and Räisänen (2012), the emotion of fear in epilepsy was investigated. The study found that fear interacted with anticipation of having a seizure and that this emotional state influenced the subjective experience of a seizure. The fear is more than simply worrying about having a seizure and the physical injuries or implications thereof, it is also a fear of the social consequences, of worrying about the negative reactions of people. The study reported that people tend to negotiate their fears over time and, for some people, the fear of having a seizure does diminish. For others, however, this fear might grow with time, depending on the type of seizures experienced, the variability, and the frequency of these seizures. Another fear reported was the fear of losing one's identity to the illness. Those with recurrent, uncontrollable seizures cannot overcome the fear; they must incorporate it into their personal narratives and make it a part of their lives and identities.

2.1.4 Stigma

Stigma is the layering of prejudice and social discrimination that an individual with a socially devalued characteristic may experience (Link & Phelan, 2006). Traditional beliefs and cultures passed on across generations play a pivotal role developing the biases, stereotypes, attitudes, and behaviours of a society on all topics, including epilepsy. Stigmatisation includes behaviours such as labelling and targeting, or to exclude a certain group from the community at large. This stigma isolates a group and lowers their quality of life. Epilepsy is thought to be a stigmatised disorder because of the unpredictable, unpreventable, and unexplainable recurrent attacks that can alter a person's cognition and personality (Degirmenci et al., 2010).

The early history of epilepsy describes the disorder as being frightening and dangerous (Yıldırım et al., 2018). The stigma attached to epilepsy has played a role dating 3000-4000 years back (De Boer, 2010; Kirabira et al., 2019). Social stigma has been associated with epilepsy for as long as the disorder has been in existence, and still exists at present. In Indonesia, the occurrence of epileptic seizures has been said to be "karma" paying the person's dues for some wrongdoing. In Nepal, epilepsy has been regarded as a sign of weakness on the part of the victim. In India, the occurrence of epilepsy has been accredited to evil spirits acting on the individual (De Boer, 2010). Epilepsy is therefore viewed as a disease to be hidden, feared and one that is severely misunderstood. In fact, patients with epilepsy were previously kept in asylums and prisons as a means of socially isolating them from society (De Boer, 2010; Kirabira et al., 2019). Due to the prevalent stigma, some families hide their afflicted children, and more individuals remain untreated (Peltzer, 2001).

In 1997, the WHO launched a campaign called “Out of the shadows.” The campaign approached the various factors and issues associated with the stigma inflicted on persons with epilepsy (Reynolds, 2001). The Global Campaign Against Epilepsy made its mission statement: “To improve the acceptability, treatment, services, and prevention of epilepsy worldwide”. Another issue that the campaign addressed was the treatment gap – this refers to the disproportionate number of individuals receiving treatment in developed versus developing countries. The Gap Action program was implemented to target low-income countries specifically (De Boer, 2010). According to Kirabira et al. (2019), the stigma attached to epilepsy has multiple effects on the individual, such as low self-esteem, poor quality of life, poor academic achievement, higher mortality rates, and even poorer health-regulatory behaviour.

Most stigmatising conditions are detectable by a physical defect. Epilepsy, however, differs in that it often lacks this visual defect and may remain invisible. Visible conditions allow people to form friendships where the disability is explicit and is a known factor in the friendship. With invisible disabilities like epilepsy, people often enter friendships, keeping their diagnosis hidden. This may result in a strain of whether to display honesty or to hide out of fear of discrimination. The choice to disclose one’s condition may be compromised by the occurrence of a seizure in public. However, if the seizures are well-controlled through medication, the decision to disclose one’s disorder or to keep it hidden stays intact. The anticipated social consequences influence one’s willingness to disclose one’s condition (Sheridan et al., 2016). In a recent study by Sheridan et al. (2016), university students living with epilepsy reported that perceived stigma was a barrier to disclosing their epilepsy and that this perceived stigma greatly increased the prevalence of anxiety and depression among these university students. Studies have suggested that the social prognosis of epilepsy is usually much worse than the actual clinical prognosis and therefore it would be ineffective to consider epilepsy as merely being a neurological disorder. The social prognosis is worsened by the stigma attached to the disorder. This stigma is founded upon low self-esteem, high levels of anxiety, and increased depression (Yıldırım et al., 2018).

The stigma surrounding epilepsy is partly due to the lack of knowledge, misconceptions about the disorder, and negative attitudes of societies. A lack of knowledge about the disorder increases negative outcomes and patients tend to have more difficulties in coping with both the clinical aspects and the psychosocial aspects of the disorder. Patients find adapting to, and managing the disorder challenging (Yeni et al., 2018). A lack of understanding about epilepsy on the part of the person with epilepsy as well as their peers may result in social stigma (Asato et al., 2009).

A clinical diagnosis of epilepsy carries a silent social stigma (Deegbe et al., 2019). There are two types of stigma – enacted and perceived. Enacted stigma is experienced as the actions and views of external sources and is met by refusal of employment, avoidance or rejection by society and potential partners (Deegbe et al., 2019). Perceived stigma is felt and internalised. This becomes an issue when persons with epilepsy do not have sufficient knowledge about the disorder, and they tend to adopt and internalise the misconceptions widespread in society. They tend to conceal their disorder; avoid social relations and isolate themselves. Some misbeliefs state that epilepsy is contagious or a punishment from God, that persons with epilepsy have poorer cognitive abilities, and that they should not participate in any social activities. This in turn increases negative attitudes and reduces self-management on the part of the patient (Yeni et al., 2018).

Stigmatisation of epilepsy is still a prominent issue today, as seen in a recent study by Mbelesso et al. (2019). This study was conducted on adolescents with epilepsy in Central Africa which revealed that more than half the population in the studied area did not acknowledge epilepsy as a medical condition and held the belief that it could be cured by spiritual means. A qualitative study conducted in South Africa (Keikelame & Swartz, 2013) in which a lay person’s experience with epilepsy was documented, revealed that lack of knowledge and cultural beliefs could contribute to the suffering of a person with epilepsy. A recent quantitative study by Adjei et al. (2018) showed that there was a higher stigma attached to people with epilepsy than to people with HIV/Aids. The negative attitude of society towards individuals with epilepsy prevails, even as more information about the disorder becomes available (Adjei et al., 2018).

2.1.5 Epilepsy in South Africa

The prevalence of epilepsy in 2015 was estimated to be around 69 million people worldwide, 13 million of whom are situated in Africa (Gilani et al., 2015). In addition, 80% of people diagnosed with epilepsy in Africa do not receive adequate treatment (Gilani et al., 2015). South Africa specifically, has a high density of people diagnosed with epilepsy. Approximately 1 in every 100 persons in South Africa is diagnosed with epilepsy (Keikelame & Swartz, 2013).

Despite these high prevalence values, the burden of epilepsy in South Africa is still thought to be relatively unknown (Gilani et al., 2015).

In a developing country like South Africa, factors contributing to the burden of effectively treating patients with epilepsy include inadequate healthcare structures, lack of trained healthcare professionals, lack of drugs, diverse spiritual practices, as well as the belief that epilepsy is a non-treatable disorder (de Boer et al., 2008; Gilani et al., 2015). There is a lack of government action in terms of spreading awareness and implementing diagnosis and treatment centres for epilepsy (Keikelame & Swartz, 2016). The socioeconomic and cultural constraints in low-income countries make the diagnosis of epilepsy even more difficult (Beghi et al., 2019). The health system in South Africa is dealing with emerging non-communicable diseases characterised by poverty and marginalisation. Epilepsy is, however, not one of these disorders and hence does not receive equal attention, even though it is among the top six non-communicable disorders treated at primary healthcare settings (Keikelame & Swartz, 2016).

Epilepsy is also known to be one of the most common neurological disorders in children with an incidence rate of 40 to 50 per 100 000 children (Wirrell et al., 2011). This means that epilepsy affects about 0.5% to 1% of the world's population of children (Asato et al., 2009). Accurate figures on the prevalence of epilepsy amongst children in South Africa are lacking and there is inadequate availability of appropriate special needs education, a lack of treatment centres, a prevailing misconception of epilepsy as a spiritual disease, as well as limited resources (Williams et al., 2015). Adolescents diagnosed with epilepsy face the obstacle of managing the disorder due to limited resources and extensive cost. Treatment centres may for instance be few and located far from the community, requiring patients to travel considerable distances (Williams et al., 2015). These adolescents do not only struggle with managing the disorder, but also face emotional and social challenges, as the stigma attached to the diagnosis results in social isolation, exclusion, and lack of community support (Ackermann et al., 2019; Williams et al., 2015).

In resource-limited South Africa, children with epilepsy, and particularly those with further disabilities, face barriers to initial care, continuation of care, poor availability of health care services, and poor acceptability of epilepsy due to cultural beliefs and stigmatisation. Practical barriers such as lack of availability of transport for the child with a disability is also a norm in our setting. These barriers influence the quality of life and long-term outcomes of children living with epilepsy in the South African context (Ackermann et al., 2019).

2.2 Adolescence

Adolescence is a development stage identified as the transitional phase between childhood and adulthood. It is marked by biological growth, social development, and several changes attributed to the occurrence of puberty (Sawyer et al., 2018). Adolescence is further defined as a stage in life at which social and psychological development take place and emphasis is greatly placed on peer support and formation of self-identity. The effects of epilepsy and the stigma attached could become a hindrance to this essential growth period resulting in frustration and ineffective management of the disorder (Wilde & Haslam, 1996).

All adolescents experience biological, social, and psychological changes. These changes influence the emotional and behavioural decisions that adolescents tend to make, ultimately shaping their personalities into adulthood. According to Erickson's stages of adolescence, late adolescence consists of increased risk-taking behaviour, family conflicts, contrasting values, and a greater need for privacy (Camfield et al., 2017). The current study will make use of this psychosocial and developmental definition of adolescents although other definitions will be shared throughout the chapter. For the purposes of this study, the term adolescent refers to an individual in the range from 13 to 19 years of age.

According to Camfield et al. (2017), from a neurological standpoint, adolescence is the time at which multiple changes occur in the brain structure. These include changes in ventral blood flow, white matter density, and neurotransmitter activity. Changes during adolescence also take place at the prefrontal cortex, a structure of the brain responsible for executive functions such as planning, decision making, and regulating emotions. These neurological changes influence the adolescent's ability to responsibly manage their health – from engaging in risky behaviour, to responsibly taking their medication (Camfield et al., 2017).

2.3 Adolescent epilepsy

Epilepsy is the most common childhood-onset disorder that transfers into adolescence, affecting 15 million children around the world (Asato et al., 2009). A large proportion of epilepsies have a childhood onset (Camfield & Camfield, 2015; Riechmann et al., 2019). The adolescent faces social, emotional, physical, psychological, behavioural, and intellectual disabilities pertaining to epilepsy, making it a complex disorder. These disabilities may continue in adulthood or stop at adolescence. The social developmental issues experienced in this transitional phase of moving from childhood to adulthood influence identity, autonomy, and have long-term psychosocial consequences (Geerlings et al., 2015).

2.3.1 Aetiology and types of adolescent epilepsy

Adolescent-onset epilepsies have a diverse range of aetiologies including structural, genetic, infectious, metabolic, and immune factors. About half the cases of epilepsy, however, present with an unknown aetiology (Fine & Wirrell, 2020). Multiple types of epilepsies are seen in adolescents' development (Wirrell, 2016). Juvenile Absence Epilepsy is the less common, genetic general epilepsy that accounts for 1 to 2% of epilepsies. The onset age is 10 to 12 years. With this type of epilepsy, about 80% of patients experience generalised tonic-clonic seizures. About 20% of these are accompanied by myoclonic jerks. It is usually a life-long illness and about 60% of affected persons can attain total seizure control with the help of medication. The remaining 40% continue to experience ongoing infrequent seizures development (Wirrell, 2016). Juvenile Myoclonic Epilepsy is the most common and accounts for 5 to 10% of all epilepsies. This type of epilepsy occurs between the ages of 12 and 18. Most of these people with epilepsy experience generalised tonic-clonic seizures triggered by sleep deprivation, alcohol consumption, flashing lights, or stress. Most cases also present with myoclonic jerks that occur early in the morning in response to sleep deprivation. Most of the cases can be controlled well with medication such as Valproic acid. These medications may have adverse effects, including weight gain, polycystic ovary syndrome, neural tube defects in pregnancy, as well as cognitive concerns for their offspring (Wirrell, 2016). Juvenile Absence Epilepsy and Juvenile Myoclonic Epilepsy fall under the generalised epilepsy type. Other epilepsies fall under focal, combined generalised and focal, and unknown type (Chang et al., 2017). Temporal lobe epilepsy is the most common type of focal epilepsy accounting for 66% of focal epilepsy diagnoses. This type of epilepsy often does not respond to drug treatment in up to 71% of patients and is commonly treated surgically (Abarrategui, 2021).

2.3.2 The transitional period of adolescence in epilepsy

Adolescents face many challenges, such as acceptance from peers, academic pressure, and striving for independence from their parents (Marin, 2005). Epilepsy has an impact on both health, and quality of life. It could impair the development of peer relationships, self-esteem, independence, and social functioning. These developmental milestones are essential in adolescence. It is during this process of development that the adolescent develops a sense of identity and autonomy, and makes many interpersonal, academic, and career-related decisions (Thomson et al., 2014). Adolescents with epilepsy must cope with their condition and treatment as well as with the challenges of a regular adolescent, such as striving for autonomy and establishing themselves into young adults (Marin, 2005; Nordli, 2001). One such affected form of autonomy is driving. Driving a vehicle is a major event in adolescence and symbolises maturity and independence. This milestone is unattainable for adolescents who have persistent, uncontrolled seizures and this is seen as a major limitation for these adolescents. In some cases, the desire to drive could serve as a motivation for treatment adherence (Marin, 2005).

The condition of epilepsy often becomes an obstacle to attaining independence and this manifests in low morale. Such adolescents therefore are at a higher risk of depression, stigma, drug experimenting, anxiety, and so forth. These conditions, in turn, increase seizure frequency, resulting in an endless cycle (Marin, 2005). Impaired development often results in issues carrying forward into adulthood. This is seen in the low marriage and high unemployment rates among adults who developed childhood-onset epilepsy, compared to the general public (Thomson et al., 2014). Even full remission of epilepsy cannot guarantee a long-term positive outcome of this transition to adulthood (Geerlings et al., 2015).

Managing a neurological disorder such as epilepsy during the transitional period of adolescence could interfere with expected life trajectories. Epilepsy, being an invisible disability, can impair the life of a student, as it presents unique challenges when adapting to adolescent life changes, such as the transition to university studies, or forming new relationships. The stress and emotional burden of these relationships may contribute to the occurrence of a seizure (Marin, 2005). The decision to disclose one’s condition to peers is a complex one for most adolescents living with epilepsy. While choosing to disclose their diagnosis could foster support and closeness among peers, it could alternatively add to experiencing discrimination and stigma from these peers (Sheridan et al., 2016). At puberty, it becomes increasingly important for adolescents to act as their peers do and to do things that others in their same age group are doing. Many adolescents conceal their disease status out of fear of losing their position or being bullied (Eklund & Sivberg, 2003).

Adolescence is also marked by biological and hormonal changes as these young people undergo puberty. The changes that occur during puberty are reported to have an influence on epilepsy, though the actual relationship is not fully known. Females, in particular, experience fluctuations in hormone levels during their menstrual cycle and these hormone levels in turn may influence the symptoms of epilepsy. Oestrogen appears to be a proconvulsant and progesterone inhibits seizures. This ratio of oestrogen to progesterone changes between ovulation and menstruation and when progesterone decreases, seizure frequency increases (Marin, 2005).

In a study by Eklund and Sivberg (2003), adolescents living with epilepsy reported that they felt different, perceived a lack of knowledge about epilepsy in society, and found it difficult to make friends. Some adolescents hid their disorder in fear of losing their position in peer groups. According to a study undertaken by Thomson et al. (2014), adolescents living with epilepsy identified day-to-day activities and social participation as the most critically affected areas of life. These disruptions include being unable to obtain a driver’s license or reluctance to participate in social events out of fear of experiencing a seizure. The adolescents identified themselves as being different from their peers and reported experiencing negative social attitudes. Peers perceived epilepsy to be “strange” or “weird” and these labels were found to have an impact on the emotional well-being of the adolescent with epilepsy. Such emotional distress may result in comorbidities such as anxiety or depression. The study indicated a critical interrelationship between social isolation, emotional dysfunction, negative peer attitudes and mental health comorbidities (Thomson et al., 2014). The reactions and silence around their disorder could also result in a seriously debilitating manner of thinking and communicating about their disorder as future young adults (O’Toole et al., 2016).

Epilepsy is unique in that it is chronic, yet intermittent. One could go months, or even years, without experiencing a seizure and then suddenly relapse. Either way, individuals are unsure when their next seizure will occur. This unpredictability feeds the complexity of adolescence, making it physically and emotionally chaotic (Nordli, 2001). Ultimately, the goal is to help adolescents with epilepsy make the successful transition towards independent adulthood with stable seizure control. This period of transition in an adolescent with epilepsy is said to occur between the ages of 13 and 19 (Camfield et al., 2017).

2.3.3 Comorbidities in adolescent epilepsy

Childhood-onset epilepsy results in multiple cognitive impairments and comorbidities that make this transition difficult (Camfield et al., 2017). Intellectual disability and learning disorders are common in people with epilepsy (Tolchin et al., 2020b). About 40% of people with epilepsy between the ages of 4 and 15 have one or more neurological conditions; most commonly intellectual disabilities, speech, and language difficulties. Cognitive dysfunction could be due to AEDs, seizure patterns, and frequency and may have a long-term effect on patients' everyday functioning (Mula & Sander, 2016). Children with epilepsy, with or without cognitive disabilities, are at a risk of underachieving academically, because the psychosocial and behavioural comorbidities could influence this (Geerlings et al., 2015).

Adolescents with epilepsy experience a more difficult time to adapt and they experience greater behavioural consequences, such as aggression, self-harm, and tantrums (Camfield et al., 2017). About 25% of all childhood epilepsies are treatment-resistant, which means that these persons experience debilitating seizures that cannot be controlled by medication. These uncontrollable seizures have a severe impact on emotional well-being, quality of life, behaviour, and cognitive development (E. Wirrell, 2016). Epilepsy in adolescence can negatively impact biological growth, the process of psychosocial maturation, and the attaining of independence (Asato et al., 2009).

Some children with epilepsy take AEDs and must avoid triggers such as fatigue. About 80% of them have an associated behavioural disorder and/or cognitive impairment. Studies show that they have a lower quality of life (QOL), low self-esteem, experience social stigma, and demonstrate low academic achievement, especially with high seizure frequency. It is thus important for children to understand the disease and how to cope with it as well as to address their needs and concerns (Chong et al., 2016).

Epilepsy in adolescence marks a period of potential vulnerability as adolescents may experience hormonal imbalance, and impaired psychosocial and biological development (Asato et al., 2009). Depression, sleep problems, behavioural issues, and cognitive impairments may also occur. These comorbidities further disrupt other aspects of the adolescent's life, such academic performance and social functioning (Asato et al., 2009). This complexity suggests that the disorder requires a multidisciplinary approach rather than being viewed as a rigid chronic illness (Geerlings et al., 2015).

2.3.4 Paediatric care to adult care

Adolescence marks a period of transition from childhood epilepsy to adult epilepsy. This transition is one of importance for the person with epilepsy, as it means changing from paediatric care to adult care and treatment in order to manage this lifelong disease (Camfield et al., 2017; Geerlings et al., 2015; Lewis & Noyes, 2013). Young people need to master self-care and self-management to gain control over their epilepsy and general well-being. Adolescence is marked as the period of independence and adolescents often feel they can manage their disorder alone instead of moving from paediatric care to adult care. This disengagement from healthcare could have serious consequences on the health and well-being of the adolescent (Lewis & Noyes, 2013).

The transfer of care from paediatric care to adult care is not seamless and often results in some complications before a new equilibrium is reached. The paediatric neurologist could for instance provide insufficient information specific to the patient's past medical conditions and the consequences of this may be irreversible medical problems. The timing of transition, revision of previous diagnosis, and revised AED prescriptions could all influence the transition of healthcare (Geerlings et al., 2015). A study by Nabbout et al. (2020) explored experiences of neurologists regarding the treatment of childhood onset epilepsies and the transition from child to adult treatment. The study revealed that the transition from child neurologist to adult neurologist was often delayed. It was also found that in many cases, there are limited child neurologists available and as a result children diagnosed with epilepsy would be treated by an adult neurologist. The study further identified that paediatric neurologists often overlooked significant adolescent issues such driving, sexuality, and professional orientation in their treatment approach. Adult neurologists were found to often have limited knowledge about paediatric epileptic syndromes and comorbidities, thus hindering treatment.

Treatment gaps in developing countries often result in delayed treatment, or lack of treatment for epilepsy. Such delay usually results in more injuries and comorbid conditions occurring secondary to epilepsy. If treatment is given on time, less seizures would occur, which would mean fewer injuries and as a result, stigma would decrease. It is therefore important to understand the factors that influence perceived stigma when planning interventions aimed at reducing this (Kirabira et al., 2019).

2.3.5 Role of the caregiver

As with most childhood chronic illnesses, epilepsy is reported to place a burden not only on the child living with epilepsy, but also on the family. This burden has an impact on family relationships, family structure, and togetherness (O'Toole et al., 2016). The role of the caregiver is crucial in adolescent epilepsy, as caregivers are the sources of information about the burden of the disease as well as the family dynamics surrounding the person with epilepsy, which in turn has an impact on the optimum management of the disorder (Asato et al., 2009).

Adolescents with epilepsy are more dependent on their caregiver, as it is usually the caregiver who maintains the treatment regime – administering of medication, doctors' appointments, diet and so forth. This attachment could potentially hinder the process of attaining independence during adolescence (Asato et al., 2009). A study conducted by Asato et al. (2009), shows that both the adolescent and the caregiver seem to experience negative outcomes due to the adolescent's seizures. These negative outcomes could be grouped into embarrassment, anxiety about experiencing another seizure, and missing family events. The study further found that treating an adolescent with epilepsy is a complex task as it requires taking into consideration the patient's specific needs and the family dynamics to improve the adolescent's quality of life. Such adolescents displayed a lower quality of life when compared to the norm – the statistical average or baseline of adolescents in the community. Their social and emotional well-being tested lower than the norms as well. More than half of the adolescents had a comorbid disorder. The study revealed that physician support and having a seizure emergency plan were indicators of better outcomes for the adolescent in terms of better treatment adherence, improved quality of life, and empowerment.

The International League Against Epilepsy (ILAE) released a statement encouraging more physical activity for persons with epilepsy with the purpose of promoting independence and self-confidence (Capovilla et al., 2016). The prevalence of parental or caregiver fears of possible injury is still very much persistent and manifests into restrictions, especially for children and adolescents. The long-term consequences of these restrictions can be parental anxiety, increased social isolation, lower quality of life for the child with epilepsy, as well as perpetuating the stigma around epilepsy through this social isolation, and the loss of the benefits of regular physical exercise (Brna et al., 2017). This statement ties in with the ILAE's previous recommendations that encouraged caregivers to only place restrictions on adolescents that are necessary to reduce stigma and encourage development. Too many restrictions would further reduce the adolescent’s ability to gain independence and may influence behavioural and psychosocial dysfunction, which may continue into adulthood (Renier, 1997). A study conducted by Berg et al. (2019) investigated the perspectives of parents of children diagnosed with severe early-onset epilepsy. Parents identified seizure severity and seizure frequency as major measures of seizure burden for the child and the parents as well. The concept of caregiver burden was explored, and the stress of seizures was identified as causing distress in all spheres of the family’s life. Several other studies have been conducted from the perspective of the parent or caregiver of a child with epilepsy, leaving the perspective of the adolescent living with epilepsy lacking in literature (Jensen et al., 2017; King-Stephens et al., 2020; Koliouli et al., 2022; Wagner et al., 2009).

A systematic review conducted on children’s experiences of epilepsy (Chong et al., 2016) revealed six major themes. The first of these was loss of bodily control. Seizures can physically manifest in dizziness and being unable to breathe, hence rendering one feeling at a loss of control. It was found that these children were constantly worried about experiencing a seizure in a dangerous place and being injured. Another physical manifestation, fatigue, left the children with less energy to partake in social or academic activities. Seizures also have cognitive manifestations such as a loss of concentration. The second theme found, was loss of privacy. The occurrence of seizures sometimes does not allow a person the choice to hide or reveal their condition and children experienced this as annoying and humiliating as the loss of motor control. They also reported that parents were overprotective due to the child’s condition. The third theme found was inescapable inferiority and discrimination. Children reported the experience of prejudice, feeling excluded, and being bullied by peers. Cognitive impairments such as memory loss and attentional problems added to low academic success and parental shame. The fourth theme, therapeutic burden and futility, was derived from the children’s beliefs that their condition was temporary and would not continue into adulthood. The AEDs have many side effects, such as weight gain, abdominal pain, and poor concentration. The fifth theme found was navigating healthcare from childhood to adult care and the need for self-management and empowerment. The last theme that surfaced in this study was the theme of recontextualising to regain normality. The identified themes reflect the emotional, social, and cognitive complexities experienced by children with epilepsy.

2.4 Conclusion

As mentioned previously, the prevalence of epilepsy in adolescents as well as the lack of holistic understanding of this disorder and its implications, even in the 21st century, and especially from the perspective of the adolescent, highlighted the need for further research. From the literature cited and the studies conducted thus far, it was evident that epilepsy transcends its identity as a neurological disorder and is rather complex and multi-dimensional in its manifestations and the treatment required. Numerous studies highlighted the perspectives of healthcare workers and parents who deal with children with epilepsy. There is, however, limited research from the perspective of the child or adolescent living with epilepsy, specifically in the African context (Pauschek et al., 2016). A study by Keikelame and Swartz (2013), pointed out the lack of qualitative research regarding the experience of living with epilepsy in South Africa. Most qualitative studies conducted in Africa have focused on young children and adults. The perspective of the adolescent is still limited, especially in Africa (Anguzu, 2020). The literature therefore identified a gap in research when it comes to understanding and exploring the experiences in the life of an adolescent with epilepsy from the perspective of said adolescent, and even more so in a developing country such as South Africa.

In the next chapter the theoretical framework of the current study is explored. The ontology, epistemology, and methodologies of phenomenology are described, elaborated on, and justified as to their usefulness in relation to the current study topic, aims, and objectives.

CHAPTER 3: THEORETICAL FRAMEWORK

In this chapter, phenomenology is explored as a theoretical point of departure as well as a methodology that will inform the research process outlined in Chapter 4. The researcher describes the history of phenomenology, the various schools of phenomenology, the theorists who founded these approaches, and how these schools are applied to qualitative research methods. The chapter goes on to explore the similarities and differences between phenomenology and hermeneutic phenomenology. The ontology, epistemology, and methodologies of phenomenology are then identified and described. Thereafter, IPA as a methodology is explored and the theoretical underpinnings of this hermeneutic approach to phenomenology are detailed.

3.1 Phenomenology

The definition of phenomenology as a theoretical framework as well as an approach to research is discussed. The history and evolution of phenomenology are also explored in the subsections to follow.

3.1.1 Defining phenomenology

Phenomenology encompasses both a philosophical world view as well as collection of approaches to research (Kafle, 2013). Phenomenology is defined as the study of lived experience (Laverty, 2003; van Manen, 2016). It is a qualitative research methodology that produces rich, in-depth descriptions of the phenomenon as well as insight and meaning as to how the phenomenon is experienced by the individual (Kafle, 2013). This experience is based on the individual’s account and not on prior knowledge or external insight regarding the event (Laverty, 2003). It questions what the experience was like and attempts to find meaning through inquiry. Phenomenology is about the journey taken towards understanding or finding meaning in lived experiences (Polkinghorne, 1983).

Merleau-Ponty (1962), as cited in Kafle (2013), identifies four core themes of phenomenology – description, reduction, essence, and intentionality. Merleau-Ponty (1962) identifies that the aim of phenomenological research is to provide a description of the phenomenon. Reduction is the bracketing of the phenomenon, so the thing itself can be returned to. Essence is the core of what makes the phenomenon what it is. Intentionality refers to consciousness.

Phenomenology has the potential to explore the depths of human experience, trace the essence of a phenomenon, and describe the phenomenon in its original form, as experienced by the individuals (Kafle, 2013).

Research, from a phenomenological standpoint, is conducted to gain insight into how human beings experience the world they live in, with the intent to get to know, in more depth, this world and in the process to better understand and become more integrated in the world. This research – to get to know the world – is referred to as "intentionality" in phenomenology. It is where researchers have the "intent" to get to know the essence of an experience and to uncover what is true and what is most important. It is a caring approach to research, because the participant's own subjective views, emotions, and experiences are explored (van Manen, 2016).

3.1.2 Husserl – the father of phenomenology

Phenomenology is rooted in philosophy and later emerged in psychology (Laverty, 2003). Although phenomenology can be traced back to Kant and Hegel, it is Edmund Husserl who is seen as the father of the philosophy of phenomenology as it is understood today (Groenewald, 2004; Laverty, 2003). Husserl mentioned that the truth could either be phenomenological, meaning real; or it can be natural – which is our everyday understanding of the phenomenon. This idea of multiple truths is echoed in traditional eastern cultures around Asia (Kafle, 2013).

Husserl criticised psychology for applying methods used in natural sciences to humans, as he debated that human beings were living, thinking, beings who applied meaning to a situation and did not simply react to external stimuli. He believed that this manner of studying human beings ignored context and created an artificial, unauthentic simulation of a much more complex being (Laverty, 2003). He advocated that people could rely on their immediate experience of things and that anything external to people's personal consciousness is unreliable and should be ignored. Husserl argued that reality lies purely in phenomena, and this was the only source of data to begin with. This science of focusing purely on phenomena became known as "phenomenology", as Husserl called it (Groenewald, 2004).

According to Husserl, common events are taken for granted and phenomenology offers insight into these and the opportunity to uncover new meaning and understanding of these everyday events (Laverty, 2003). The goal of phenomenological research is to study phenomena as they appear in the consciousness of the individual. According to Valle et al. (1989), as cited in Laverty (2003), Husserl viewed consciousness as the dialog between a person and their world and he claimed that this consciousness was the doorway to understanding one's world. Husserl viewed consciousness as purposeful, as an individual could delve into their consciousness and with intent, construct their own realities, hence explaining the way events may be the same but the way that they are experienced by different individuals remains unique (Laverty, 2003).

It was Husserl who initiated the phenomenological movement as a radical new way of conducting philosophy. Later, theorists such a Heidegger moved away from the philosophical view that dealt with essence and consciousness of a phenomenon to more hermeneutic or interpretive practices of phenomenology (Laverty, 2003).

3.1.3 Heidegger's contributions to developing phenomenology

Martin Heidegger (1889-1976) was a student of Husserl's and introduced the concept of a dialog between the person and their world. Both Husserl and Heidegger explored the lived world within the concept of an existence in the regular world (Groenewald, 2004). A follower of Husserl and Heidegger, Alfred Shultz (1899-1956), introduced the idea that various meanings could be extracted from the experience of the human world (Groenewald, 2004). Heidegger was trained by Husserl and taught phenomenology and reduction. Once he become proficient in the field, he dissociated himself from Husserl and followed his own route. Like traditional phenomenology, hermeneutic phenomenology, too, is concerned with the study of lived experiences (Laverty, 2003).

The two differed in their manner of exploring lived experience. According to Jones (1975), as cited in Laverty (2003), Husserl focused on understanding phenomena and Heidegger focused on something called "Dasein" which translates to understanding what phenomena meant to the individual. Husserl viewed humans as knowers who recall facts and perceive experiences, while Heidegger saw humans as curious and concerned in an unknown world (Laverty, 2003). Heidegger believed that consciousness formulated experience and that understanding was what human beings were, and not merely how they understood the world (Polkinghorne, 1983).

Understanding comes from one's background and environment. Culture, beliefs, and traditions play into how a person sees and understands the world. Heidegger saw cultural, social, and historical contexts as meaningful to one's construct of reality. Heidegger believed that a person could not simply step out of their experiences and biases and remain completely neutral, and that nothing could be understood without influence from a person's background (Laverty, 2003). According to Koch (1995), as cited in Laverty (2003), meaning is made as we are constructed by the world, and we construct the world from our own experience and background.

3.1.4 Critique of the phenomenological approach

Pure phenomenology is criticised for relying on subject matter alone – that it purely relays descriptions of phenomena without any reflection or introspection, which undermines its claim to be a true intellectual discipline (Noë, 2007). Furthermore, the claim of phenomenology that it is realistically possible for a researcher to bracket their own opinions and biases is questioned.

Phenomenology in its traditional form is often criticised, as phenomenological facts are seen as being independent or "freestanding" from empirical knowledge and facts. In rebuttal to this statement it can be argued that since the purpose of phenomenology is the matter of how things seem to us, it is autonomous from empirical and metaphysical assumption. This autonomy, according to Husserl, is exactly the purpose behind phenomenological knowledge – to neutralise data from the effects of empirical and metaphysical restraints (Noë, 2007).

Authors such as Dennett and Kosslyn made claims that phenomenology cannot truly contribute any genuine scientific explanations of consciousness (Gallagher, 1997). In contrast Marbach (1993), as cited in Gallagher (1997), argued that phenomenology provides reliable and systematic reflection and analysis that can aid in guiding empirical and cognitive sciences.

Another criticism of phenomenology is its view of perspective. According to the phenomenological stance, perceptual experience is concerned with the presence and involvement of situations and things in the world. In the absence of engagement with the objects and situations, phenomenology would assume a lack of perceptual experience (Noë, 2007). Hermeneutic and interpretive phenomenology serve to address many of these critiques, as will be discussed in the description of these branches of phenomenology in this chapter.

3.2 Descriptive phenomenology vs. hermeneutic phenomenology

Laverty (2003) identifies that the biggest difference between classic phenomenology and hermeneutic phenomenology is self-reflection in which the data is considered by reading, reflective writing, and interpretation. When applied to research, there are two distinct approaches to phenomenological research – descriptive and interpretive (hermeneutic) phenomenology (Willig, 2013).

3.2.1 Descriptive phenomenology

Applied to research, phenomenology is the study of the phenomenon at hand (Kafle, 2013). All phenomenological research is descriptive in its initial stages. Focus is on the structure of the lived experience and what gives meaning to the lived experience and the world in general. The essences of these meanings are revealed through this type of research (Polkinghorne, 1983). The researcher describes the lived experience from a first-person account of the participant without imposing generalisations. The researcher then analyses these descriptions and synthesises them into themes and attempts to expose the meaning and essence of the phenomenon at hand (Finlay, 2009).

The aim of descriptive phenomenological research is to describe the essence of a phenomenon (Smith et al., 2009). Emphasis is placed on discovering the core characteristics that define the phenomenon. Husserl proposed the concept of bracketing or reduction, in which one needed to bracket out one’s own biases, beliefs and assumptions in order to successfully conduct a phenomenological study and acquire the essence and true meaning of a phenomenon (Laverty, 2003). Thus, the researcher’s role in this type of phenomenological research is to bracket their past knowledge and assumptions and objectively describe the account of the participant (Willig, 2013).

3.2.2 Hermeneutic phenomenology

Interpretative phenomenology comes from a hermeneutic approach introduced by philosophers such as Heidegger and Gadamer. Heidegger argues that interpretation is not something added, it is in fact the mere being of the researcher in the world that causes interpretation to occur (Finlay, 2009). Hans-Georg Gadamer founded the school of phenomenology known today as hermeneutic phenomenology. He saw hermeneutics as a procedure of understanding, and further clarified that the person who seeks to understand phenomena should have some bond with the phenomena being studied. Gadamer, just like Heidegger, viewed language and understanding as inseparable aspects when the goal is to understand human beings and he, too, reiterated that interpretation stood with understanding. Interpretation fused the expectation of the interpreter and the meaning of the text. Expectations and meaning are the horizons fused together by interpretation to see the whole picture (Polkinghorne, 1983).

Hermeneutic phenomenological research is interpretive and is dependent on the historical meanings of experience and the impact thereof on individuals. This process of interpretation looks at the beliefs and assumptions of the individual that allow them to make these interpretations (Polkinghorne, 1983). In interpretive phenomenology the meaning of a phenomenon is uncovered through the process of interpretation. It is assumed that we get to know about the world through understanding and that interpretation is a critical process in understanding. The researcher interacts with the reality of the participants and through interpretation uncovers the meaning of the phenomenon (Laverty, 2003).

An important aspect of hermeneutic phenomenology is seeing things and understanding and finding meanings that were not previously visible. According to Gadamer (1976), as reported by Laverty (2003), it is more than just re-creating another person’s meaning; it is dynamic, and the insertion of oneself changes what one had known and had understood before. Interpretation is dynamic and always evolving (Annells, 1996). Gadamer (1976) believed that bracketing was impossible. He did not believe that one could abandon one’s background and preunderstanding to adopt a new attitude and he advocated that this presence of preunderstanding could actually play a positive role in the search for meaning (Laverty, 2003). This approach is focused on the subjective experience of individuals or groups. It is an attempt to view the world as experienced by the subject through their world stories. It is believed that interpretations are what we have and that description is interpretive in nature (Kafle, 2013).

Interpretation is seen as a core aspect of understanding, as every encounter involves interpretation in one way or another and this interpretation is heavily based on one’s background. Hermeneutics is an interpretive process that brings meaning to phenomena through language. Texts are written to include visual cues, hand gestures, music, and verbal communication (Laverty, 2003). As all understanding is influenced by one’s background, Heidegger advocated that it is essential to remain aware of these interpretive influences. This brings about a hermeneutic cycle in which one moves from understanding parts of a text to the whole text and back and forth to increase the depth and richness of understanding the text (Annells, 1996; Polkinghorne, 1983).

3.2.3 Hermeneutic phenomenological research paradigm

A paradigm is defined as a collection of logically related assumptions or propositions that direct thinking and research. When applied to qualitative research, the paradigm consists of metaphysics, methodology, quality, and ethics. The metaphysics consist of the ontology, epistemology, and axiology. The researcher's epistemological and ontological position determined and informed the chosen methodology and the processes of the research study (Kafle, 2013). When applied to hermeneutic phenomenological research, reality is a construct dependent on the individual and the situation. Realities are said to be multiple (Kafle, 2013).

The positivistic paradigm, though partially similar to the descriptive branch of phenomenology, was found insufficient, as it could not capture the essence of human experiences – values, meanings, intentions, and human experience. Unlike positivism, the phenomenological paradigm focuses on human consciousness and essences. It is therefore a way of understanding the world as well as a method of inquiry (Kafle, 2013).

Epistemology is concerned with how it is we know what we know and relies on the premise that the research conducted will contribute to existing knowledge. Hermeneutic phenomenology relies on subjective knowledge and assumes that knowledge can be made through subjective insight and experiences (Kafle, 2013). Epistemology is also concerned with the nature of the relationship between the researcher and what can be researched (Laverty, 2003). Positivists see the researcher as separate to the subject matter and maintain that the researcher should bracket their biases or viewpoints, as the influence of these would corrupt the data (Polkinghorne, 1983). Value-free research is criticised for the loss of knowledge about human experiences and making meaning. Interpretive phenomenology values the relationship between the researcher and what is being researched (Kafle, 2013). Polkinghorne (1983) insisted that the researcher was central in research.

Ontology is the nature of reality and what can be known about it (Laverty, 2003). When applied to hermeneutic phenomenological research, reality is regarded as an individual construct that is dependent on the context (Kafle, 2013). Positivists view the world as something that is set out with rules and general characteristics that can be identified – something apart from ourselves that we are able to receive and study, and not something that we have created (Polkinghorne, 1983). The interpretivist paradigm of inquiry supports the ontological stance of believing in the existence of multiple realities that can be constructed and altered by the knower (Laverty, 2003). Reality is specific and constructed and is not just out there. Polkinghorne (1983) describes this interpretive paradigm as an attitude about knowledge rather than a school of thought.

The ontology of phenomenology is both subjectivist and relativist. The subject matter is the meaning of being and is contextual. Phenomenology holds the assumption that individuals assign meaning to life events and this meaning shapes their lived experience (Willig, 2013). In interpretive phenomenological inquiry the researcher is not meant to bracket previous knowledge and presumptions and the researcher's bias is in fact used as a tool to further explore and understand the meaning of the phenomenon at hand. The researcher's role is acknowledged in questioning and making meaning of the phenomenon at hand (Smith et al., 2009).

While epistemology and ontology deal with truth, axiology deals with quality and ethics (Kafle, 2013). It is also called value theory and these values provide the standards by which the ontological and epistemological claims are evaluated. In terms of research literature, it refers to the values and opinions of the researcher and how these contributed to the knowledge that was generated. Interviews, observations, and protocols are used for data generation in a phenomenological study. Since the purpose of phenomenology is to generate life stories depending on context and area of research, the data collection instrument can be selected (Kafle, 2013).

3.3 Conducting a hermeneutic phenomenological study

By the 1970s, Giorgi developed a method of conducting phenomenological research. The aim of a researcher in a phenomenological study was to describe the phenomenon as accurately as possible without being influenced by any preconceived notions, yet staying true to the facts. A phenomenological researcher is concerned with the lived experiences of the people involved with the topic being researched (Groenewald, 2004).

According to Giorgi (1997), as cited by Finlay (2009), all psychological phenomenological approaches have three core characteristics: the research must be rigorously descriptive, it must rely on phenomenological reductions, that is, the researcher must bracket their prior knowledge and biases from the study at hand, and, it must search for essence and meaning. Some approaches to phenomenology adhere closely to these guidelines and others venture further away. All phenomenological researchers agree that the goal of this research is to produce a rich description of phenomena as they are experienced. Phenomenological methods aim to be responsive to the phenomenon, but also to be mindful of the merge between the researcher and what is being researched (Finlay, 2009).

A methodology is not a method that is followed, but rather a creative solution using whatever approach is needed to address the subject matter and answer the research questions posed (Laverty, 2003). When phenomenology or hermeneutic phenomenology is employed as a methodology, however, it must use and follow through with the chosen philosophy throughout the study. The methodology is more cyclic, rather than a linear step-by-step procedure (Laverty, 2003). Essence refers to the essential meaning of phenomena, that is, what makes it what it is (van Manen, 2016). A good phenomenological description is one that constitutes the essence so that a construction of the structure of the lived experience is revealed; thus, we may grasp the nature and the significance of the experience (van Manen, 2016). According to Groenewald (2004), the systematic steps for conducting a phenomenological study are locating participants, data collection, data storage, data explication, validation, and truthfulness.

The participants in a phenomenological study are selected as based on the criterion that they all share a lived experience which is the focus of the study, that they are willing to share this experience openly, and that they are diverse enough to provide rich, unique stories contributing to the study of the phenomenon (Polkinghorne, 1983; van Manen, 2016). The number of participants will vary according to the nature of the study. The researcher should engage with the participant until saturation is reached, a point after which no deeper or better understanding of the experience will be gained through further exploration (Laverty, 2003).

Reflection is a major part of the data analysis process, during which the researcher must self-reflect on their biases and become aware of these biases or presumptions. In descriptive phenomenology, the purpose of this is to bracket these biases and make sure they neither impose on, nor influence the study. In a hermeneutic phenomenological study, however, this process of self-reflection serves quite differently. Instead of bracketing these biases, they are seen as essential to, and embedded into the interpretive process. The researcher must remain transparent throughout the study and reflect on how their own experience and beliefs influence and interact with what is found in the study at hand. These reflections are kept in a reflective journal (Laverty, 2003).

Researcher subjectivity is acknowledged by phenomenologists and this subjectivity is deemed inevitable. The interconnectedness of the researcher and what is being researched is central to phenomenology. Different approaches advocate for different degrees of how heavily influential the subjectivity of the researcher should impact on the study. The researcher must adopt a phenomenological attitude, that is, to engage oneself in an open manner to phenomena and to the subject being researched. How much the researcher brings their own experience into the data, and to what extent they are subjectively reflexive about this experience, is debated in the various approaches to phenomenological research (Finlay, 2009).

Reduction means reducing and removing oneself to be as noninfluential and as neutral as possible and to bracket one's own assumptions, opinions, and experiences, and to view the phenomenon of concern at face value. Bracketing is not a first step but is rather carried on throughout the research process. The hermeneutic approach to phenomenology advocates that it is in fact neither possible, nor beneficial to bracket the assumptions and experiences of the researcher – this is not strictly adhered to in the IPA hermeneutic approach. This branch of phenomenology believes that the researcher should be fully aware of and examine their previous experiences and apply this to the newly found evidence. This subjectivity should be fully disclosed so that it is clear as to what beliefs belong to the researcher and which to the participant (Finlay, 2009).

3.3.1 Interpretative phenomenological analysis

Smith's phenomenological method, IPA focuses on rich descriptions of lived experiences, but does not explicitly follow all of the principles of traditional Husserlian phenomenology (Finlay, 2009). This method of IPA is idiopathic and inductive as it seeks to understand the lived experiences of individuals and is phenomenological in its appreciation of the individual's perspective. IPA, however, relies on a more hermeneutic approach to phenomenology in that the role of the researcher is seen as central and the idea of bracketing is not embraced as it is in a traditional phenomenological approach (Finlay, 2009; Smith, 2004).

IPA has three broad elements. It represents an epistemological position, is a set of guidelines for conducting research, and is a collection of research. Theoretically, IPA aims to explore the details of one’s lived experience and how participants make sense of their lived experience. IPA follows phenomenology in its concern with the participants’ perceptions of experiences and phenomena. IPA is also concerned with the researcher’s role in making sense of the perceptions of participants – thus making this method interpretive or hermeneutic in nature. A double hermeneutic exists in IPA – the participant is trying to make sense of his/her world and the researcher in turn is trying to make sense of the participant’s making sense of his or her world (Smith, 2004).

IPA makes use of a small sample size of around 10 participants, which may be seen as a limitation (Pringle et al., 2011). However, Smith et al. (2009) suggests that smaller sample sizes allow for a deeper and more interpretative analysis that may not be possible for larger samples. Smith et al. (2009) provide a set of steps to be followed in conducting IPA, but also stress that these steps are flexible and may be adapted in response to different contexts. This complexity of openness can prove to be a methodological issue for researchers who are used to a more rigid and structured approach to scientific experimentations and research (Pringle et al., 2011). The implementation of IPA as a methodology will be described in detail in Chapter 4.

3.4 Conclusion

This chapter outlined and described the theoretical journey of phenomenology and also explored how the theory is applied to qualitative research in psychology. The schools of phenomenology were highlighted with special mention of the hermeneutic approach to phenomenology that forms the theoretical basis of the study at hand and IPA as a method of analysis. The application of these theoretical underpinnings and approach to research are further explored and applied to the study at hand in the next chapter, which details the research methodology for the study.

CHAPTER 4: RESEARCH METHODOLOGY

In this chapter the methodological considerations that inform this study will be discussed. This chapter provides a rationale for choosing a qualitative research approach to address the aim and objectives of the study and also provides an overview of phenomenology as the chosen methodology. Furthermore, the chapter explores the research design, the sampling process and inclusion criteria, the use of in-depth interviews as a data collection method, and the use of IPA as the method of data analysis, all within the theoretical framework of phenomenology. The chapter continues with a discussion on the criteria for quality control of the qualitative study at hand. In conclusion, the ethical considerations and reflexivity applied throughout the research process are discussed.

4.1 Research design

In the subsections on research design, phenomenology is described as the theoretical framework (see Chapter 3) and the methodology of the study. The qualitative approach is described within a phenomenological realm. The aim, objectives, and research question of the study are outlined.

4.1.1 Qualitative research: a phenomenological approach

The researcher opted to employ a qualitative research methodology as it values understanding the subjective, lived experiences of human beings (Haverkamp & Young, 2007). Qualitative research is exploratory in nature (Ma, 2000) and enables grasping the complexities of a lived experience and drawing meaning from these experiences. Thus, qualitative research allows for an in-depth understanding of the lived experience of an adolescent living with epilepsy. The use of language as a means of data collection allows culturally-specific information to be more accurately recorded and interpreted (Mack et al., 2005).

Several approaches are used in qualitative research, such as case study research, narrative, ethnography, grounded theory and, phenomenology. Phenomenological qualitative research views the phenomenon as the subject of study and draws on the description of lived experiences of individuals or groups to attain the true essence or meaning of this phenomenon (Creswell, 2018). Phenomenology is said to be descriptive in that the lived experience of the phenomenon is described. As described in chapter 3, there are two types of phenomenology: descriptive and interpretive (Finlay, 2009) and the current researcher has opted to employ the type of phenomenology known as hermeneutic or interpretive phenomenology. The interpretive phenomenological research approach advocates that research is a dynamic process and the researcher plays an active role in the research process (Smith, 2004). IPA is an interpretive approach to phenomenology and is employed as the method of data analysis in the study at hand.

The study uses phenomenology both as the theoretical framework (see Chapter 4) as well as a methodological approach and IPA as the method of data analysis. Phenomenology, applied to research, is defined as the study of a phenomenon. The focus of the study is on the way things appear as they are experienced by the individual or in one's consciousness. The researcher's aim was to give a rich, detailed description of the lived experience (Finlay, 2009). Phenomenology is capable of extracting a deep understanding of human experience right at its core and describing this phenomenon in its original form as experienced by the individual or group (Kafle, 2013).

A phenomenological paradigm considers the participant's world from their own perspective and aims to describe the detail and diversity of their consciousness (Willig, 2013). According to Smith et al. (1999) phenomenology is concerned with the individual's experience of a phenomenon and not with the objective details of the phenomenon. This methodology was therefore deemed the best approach to achieve the objectives set out in this study. Within the phenomenological approach, the researcher chose the Interpretive Phenomenological Approach (IPA) as the method of data analysis.

In health psychology, it is imperative to understand the significance of the condition of a person's lived experience and day-to-day life (Pietkiewicz & Smith, 2014; Smith et al., 2009). IPA was selected as the method of data analysis as this method allows this in-depth understanding within the social context of the individual's life. IPA moves further than just describing the experiences of individuals, by actually interpreting these experiences and finding meaning in them (Larkin & Thompson, 2012), as will be explained in section 4.5.

4.1.2 Aim, objectives, and research question

The aim of the current study was to explore the experiences of adolescents living with epilepsy in South Africa. The objectives of the study were to explore the social, psychological, and cognitive implications of living with epilepsy from the adolescent's perspective, to explore the world view of an adolescent with epilepsy, and to explore and describe the challenges faced by adolescents living with epilepsy. The research question addressed by this study is: What are the experiences of adolescents living with epilepsy in South Africa?

4.2 Methodology

This section describes the method of sampling, outlines the data collection process, explores the method and procedure of data analysis, and takes into consideration the quality criteria.

4.2.1 Sampling

An IPA study requires a homogenous group of participants to be used. This means that the participants must share a lived experience (Willig, 2013). For the study at hand, this group comprised of adolescents living with epilepsy. Purposive sampling was used by the researcher to gather participants. This involved the selection of individuals with certain characteristics suitable to the phenomenon being studied. A purposive sample requires inclusion criteria. The inclusion criteria established for this study were guided by the criteria provided by Camfield et al. (2017) for the adolescent category of epilepsy.

In order to participate in this study, the following criteria needed to be met:

(a) Adolescents were to be between the ages of 13-19;

(b) Participants were to have been diagnosed with epilepsy (any type of epilepsy) by a medical professional/neurologist more than one year before, to ensure that they were on medication and/or had some level of symptom stability;

(c) The participants were to be proficient in English and residing in South Africa; and

(d) The participants could be of any gender and ethnicity.

IPA focuses on the detailed account of an individual’s experience and therefore usually requires a small sample size of one to 30 participants. A sample of three to six participants is suggested for undergraduate and master’s studies (Frost, 2011). Epilepsy South Africa, a non-profit organisation that enables persons with epilepsy to network and that creates equal opportunities for people with the disorder, was contacted by the researcher and they agreed to assist in recruiting the needed participants. The organisation sent out invitations to members who fulfilled the selection criteria. Those willing to participate then contacted the researcher directly via email. A parent/guardian was required to provide consent for the adolescent's participation in the study. For online interviews this was done via email. A sample size of three participants was acquired through this sampling process.

4.2.2 Data collection

Data was collected using in-depth, semi-structured, online interviews via the videoconferencing platform, Zoom, to mimic the conditions usually found in face-to-face interviews. The decision to conduct interviews online was taken against the backdrop of the Covid-19 pandemic. A national lockdown was put in place in March 2020 which enforced that people remain in their homes to in order to prevent the spread of the Covid-19 virus. The researcher therefore no longer had the option of conducting face-to-face interviews and conducted all interviews via Zoom. The first interview was conducted in July 2021 (level 4 COVID restrictions were in place at this time), the second in August 2021 (level 3 COVID restrictions were in place at this time), and the final interview was conducted in November 2021 (COVID restrictions were reduced at this time to alert level 1). The Zoom platform allowed the interviews to be conducted in real-time. Online interviews have the advantage of eliminating travel costs. They also give participants time and space, as well as the comfort of their surroundings, making it easier to discuss sensitive issues (Alase, 2017). A recent study conducted on online versus in-person interviews (Shapka et al., 2016) revealed that while duration and number of words differed between the two modes of interviewing; the number and kinds of themes, self-disclosure, formality, detail of the content discussed, and quality of the data collected was found to be equal for online and in-person interviews. Participants in the current study were compensated by the researcher for the data that they used from the interview. The researcher provided 1GB of mobile data to each participant's preferred mobile device.

In studies that make use of IPA, the topic must be something of significance to the participants and must be a topic that they have a keen understanding of (Larkin & Thompson, 2012). Individuals who had been diagnosed with epilepsy more than a year before (as required by the inclusion criteria) were bound to have a basic understanding of the illness and its impact on daily life. An interview guide (Appendix E) was used to explore key topics while allowing for flexibility in the structure of the interview (Pietkiewicz & Smith, 2014). This kind of interview facilitated interaction that was in-depth and open ended (Shinebourne, 2011). An interview guide typically begins with an open-ended question and includes prompts based on the aim, the objectives of the study, and the literature on the topic under study. The guide for the current study consisted of an open-ended initial question plus about nine prompts and was drawn up with room for elaboration and exploration in mind, which is typical in studies using IPA (Frost, 2011; Smith et al., 2009). The open-ended questions focused on the neurobiological, social, psychological, and cognitive aspects of living with epilepsy. The participants were interviewed individually, and each interview lasted for a duration of 60 to 90 minutes.

Before the interview, a brief sociodemographic questionnaire was completed by each participant to elicit information such as age, gender, ethnicity, type, and duration since being diagnosed with epilepsy (Appendix E). This was done at the beginning of the online interview. The researcher shared the screen with the sociodemographic questionnaire with the participant, read through the document with the participant, and completed the form, guided by the participant's answers to the questions. Demographic data such as gender and ethnicity aid in constructing a description of context in qualitative studies (Connelly, 2013). It is important for the researcher to establish a rapport with the participant at the beginning of the interview so that the participant feels relaxed and comfortable (Alase, 2017). This was established by engaging in a warm-up discussion with the participant where general topics such as goals or hobbies are discussed so that the participant would feel more at ease moving on to more sensitive topics (Pietkiewicz & Smith, 2014). The online interviews took place in a remote manner at the time and date agreed upon between participant and researcher. The researcher sent a Zoom link to the participant via email 30 minutes before the scheduled interview, which enabled the participant to join the online interview session. The interviews were recorded using Zoom, as the platform has a feature to securely record and store the sensitive and personal information that was collected (Archibald et al., 2019). Observational notes were also taken during the interview, and these were incorporated in the analysis and interpretation of the experiences documented.

The search for participants was not given a specific cut-off point as the researcher continued to pursue possibilities of new participants up until and during data analysis as well. According to Bernard (2012) the number of participants required for data saturation cannot be quantified but rather the researcher should take what they can get. Data saturation was deemed to be reached as no significant new themes emerged in the three interviews. In qualitative research no new themes is often synonymous with no new data (O'Reilly & Parker, 2013).

4.2.3 Data analysis

IPA is discussed in the following subsections. The rationale for using this analysis approach, the process of conducting an IPA study as well as the role of a researcher in IPA are discussed.

4.2.3.1 Interpretative Phenomenological Analysis

IPA is an approach to conducting a phenomenological study and is the method of data analysis employed by the researcher. IPA focuses on exploring lived experiences, thus allowing individuals to make sense of themselves and the world around them (Smith et al., 2009). Culture and socio-historical factors are taken into perspective (as discussed in Chapter 2). The approach combines phenomenology, investigating the subjective meanings people give to their experiences, discursive psychology, interpretations that are governed by social and cultural discourses, and it is idiographic in that it focuses on how a certain person, in a certain context, makes sense of a phenomenon (Frost, 2011). Information is not taken on the surface, but rather used to infer themes and greater meaning. It moves away from realism as a world view, as it is not important for information to reflect a factual truth in the universe, but rather to reveal subjective truths (Frost, 2011). If an adolescent with epilepsy claims to experience no stigma, for example, according to this paradigm, this does not mean that stigma is not real. It simply means that in this person's subjective truth they do not experience it. This truth may or may not be the truth of another individual. In fact, phenomenology would view the lack of an experience as an experience. Using IPA, one would go further and interpret this information beyond the face value, draw an inference, and look at the deeper meaning within the subjective view of the participant.

The outcome of a successful IPA study should provide participants with a voice to tell their story through detailed, rich, open-ended accounts of experiences, but also allow for the researcher to interpret and make meaning of these first-person accounts. The IPA method goes even further than what is rooted in the data by expanding the understanding to abstract psychological aspects (Larkin & Thompson, 2012). Quantitative studies have previously shown that the label of “epilepsy” indeed has an impact on the quality of life of persons with epilepsy. The actual experience of attached stigma and the experiences of these individuals in general, was, however, reported to be unclear (Cramer et al., 1999). Research from the perspective of the person living with epilepsy remains limited (Pauschek et al., 2016). Qualitative data, such as personal narratives, would provide a deeper understanding of the experiences of adolescents with epilepsy in South Africa.

4.2.3.2 The process of IPA

When interpreting qualitative data, it is essential that the interpretation of data should be seamlessly organised, detailed and completely transparent. This organisation lies in the finding of patterns in the data. These patterns are called “themes” in qualitative research. These themes are drawn by looking at the data and the researcher’s commentary on this data in a detailed, line-by-line fashion (Larkin & Thompson, 2012). In descriptive phenomenology, researchers are advised to “bracket” their opinions away from the “lived experiences” of the participants and not to interject their own personal experiences or preconceptions into the stories of the participants. However, a more reflective, cyclic approach to bracketing is used in IPA as it focuses on the lived experience of the participant via the researcher’s interpretation of its meaning. The researcher plays a dual role of making sense of the participant who is making sense of his/her lived experience (Alase, 2017). The process of analysis is fluid, complex, and reflective. For the sake of simplicity, however, Frost (2011) describes this process in a series of stages. The researcher used these stages as a guide when analysing each interview transcript. All of the interviews were transcribed by the researcher.

According to Frost (2011), **stage 1** of the analysis involves reading and re-reading the transcript of an individual’s interview. The researcher became acquainted with the transcript by repeated readings of each transcript as well as listening to the recording of the interview over and over. This allowed multiple opportunities to gain new insights and pay close attention to context, language, and content. The researcher actively engaged with the initial transcript so that the participant’s experience became the center focus of the analysis and only then proceeded to make interpretive notes based on the researcher’s understanding of the experience. Time was also taken to make separate notes of the researcher’s personal thoughts and reflections and how these might shape the researcher’s own understanding and interpretation of the transcripts.

At **stage 2** the researcher looked back at the transcripts and the initial notes and transformed those initial notes into core themes. The aim was to formulate themes that stemmed from phrases rooted in the transcripts and were close enough to cluster, but still vague enough to allow further exploration and drawing of abstract psychological concepts. Remaining reflexive throughout this process and being transparent about possible influences was key to the process.

At **stage 3** the transcript was examined as a whole and the emerging themes from stage 2 had to be considered and clustered according to conceptual similarities. Once these were clustered, the researcher gave a descriptive label to each cluster of themes. Thereafter a table was drawn up listing all the main themes and subthemes identified. The table consists of main themes and subthemes together with supporting quotes form the data for each theme and the line number of the transcript at which the quote could be found, making referring an easier task. The table ensured that the integrity of the participant's words was kept intact. The table drawn up constitutes **stage 4** of the analysis process.

Smith et al. (2009) further describe stages 5 and 6 of the analysis. **Stage 5** is moving on to the next transcript. The first 4 stages were repeated for the next case and this was done for each subsequent transcript. It is important to treat each case as an individual one and bracket the ideas emerging from each analysis from the next, as far as possible, thus it is idiosyncratic. It is inevitable, however, that previous knowledge would, in some way, influence what followed. The researcher remained mindful and reflexive during this process.

Once all the transcripts were analysed, and an accompanying table of themes was drawn up for each one, a final table of themes was formulated, bringing the analysis to **stage 6 –** looking for patterns across cases. The final table of themes was formulated, rechecked, and used to write a narrative report. This process required the researcher to return to the original data multiple times to verify statements and meaning. The themes were selected as based on the prevalence, richness, and meaning of extracts available to back up and verify these final themes.

The narrative report was drawn up from the final table of themes. The narrative brings together the participant data and the researcher's interpretive commentary on this. The narrative intended to take the reader through the analysis, to highlight important themes and meanings, to identify key concepts with examples from the data – in the form of verbatim quotations from the transcripts, and to explore any emerging patterns that were of significance (Larkin & Thompson, 2012).

4.2.3.3 Role of the researcher in IPA

The researcher plays an active role in the interpretation of the data during data analysis. It is therefore essential to acknowledge the involvement or impact of the researcher's own beliefs, assumptions, and ideas even before data analysis as these could have a beneficial or detrimental impact on the overall analysis of data and hence on the study itself (Thorpe & Holt, 2008; Willig, 2013). It is vital for the researcher to remain aware of these assumptions and to be reflexive throughout the research process. The researcher kept a reflective journal throughout the research process in which thoughts and opinions were documented and reflected upon. These reflections are shared and discussed, in correlation with the findings of the study, in the discussion chapter (Chapter 6).

4.2.4 Criteria for quality in qualitative research

Phenomenology is grounded in the lived experiences of a phenomenon and hence the "validity" or trustworthiness of the findings lies in the experience of the phenomenon as experienced by the individual. The findings are therefore considered trustworthy if it can reflect insight from the perspective of the participant (Baker et al., 1992). To ensure the quality of the findings, Yardley (2000) mentions four characteristics of good qualitative research and stresses that these criteria should be more about assuring quality than merely ticking off a checklist. Furthermore, it is essential for further studies that the researcher is reflective about the limitations and strengths of the study. Quality control and the ability to authenticate the findings of the study are vital in qualitative research (Alase, 2017). The criteria for quality control applicable to the current study are as follows:

4.2.4.1 Sensitivity to context, reflexivity, and documentation

The first characteristic is sensitivity to context, where the researcher is fully aware of the research in relation to relevant existing literature on the chosen topic. The researcher must be mindful of the socio-cultural context of the participants, as contextualising the interpretation is essential in qualitative research (Yardley, 2000). This can also be referred to as contextual interpretation, which ensures that cultural and personal histories, as well as their immediate settings (school, home, etc.) (Stiles, 1993) are considered.

This was achieved in two broad manners; firstly: by conducting a comprehensive, in-depth literature review on the relevant existing research and being able to identify a gap that could be addressed by the current study. This enabled the researcher to gain understanding of the existing research in various contexts and to understand which contexts had been excluded or overlooked.

Secondly, sensitivity to context is also displayed in the data analysis process in which the researcher must pay excruciating attention to every line of data from the interviews conducted. According to Smith et al. (2009) a successful IPA study displays great sensitivity to the data. It is essential to include multiple verbatim statements from the transcripts in the data analysis to back up claims and interpretations made from the data so that the participant is given a voice and is represented in the most accurate way possible.

Reflexivity also plays a part in sensitivity to data as the researcher should be mindful that the analysis is not tainted by meanings inflicted by the researcher's own understanding and bias. Measures must be taken to ensure that the findings are a reflection, as best as possible, of the ideas and experiences of the participant rather than those of the researcher themselves. Reflexivity ensures that the role of the researcher is acknowledged, as personal bias may shape the outcomes of the study (Willig, 2013).

Documentation is the detailed account of what exactly was done and the reasoning behind each step in the research process will be provided by the researcher (Willig, 2013). The researcher's interpretation may not always align with what the participant meant to say, and this is addressed by the criteria of sensitivity to negotiated realities. The researcher can address this by acquiring interpretations of the data analysis through consultations with the research supervisors (Willig, 2013).

4.2.4.2 Commitment and rigour

The second characteristic is commitment and rigour (Yardley, 2000). Commitment is a key necessity for a researcher conducting an in-depth interview. The degree of concentration, complete presence of mind, and engagement with the participant during the interview is crucial to the validity of the data collected. This commitment must further be carried forward into the data analysis process (Smith et al., 2009). During the analysis stage the researcher took steps to remain mindful and keep the analysis grounded in original data by constantly referring to a participant's own words.

Rigour refers to completeness and thoroughness, from selecting participants and making sure they meet the inclusion criteria, conducting interviews with utmost care and respect as the topic of illness is a sensitive one, and being meticulous about data analysis (Shinebourne, 2011). In this study rigour was displayed by formulating inclusion criteria specifying participants to be included in the study, through the in-depth interview process, and mindful analysis of this data.

4.2.4.3 Transparency and coherence

Yardley's (2000) third criterion is transparency and coherence. Detailed information about each step of the research needs to be disclosed by the researcher. In this study the researcher described the methods of data collection and analysis in detail. This included the researcher's motivations, assumptions, and beliefs that may have shaped the findings. Furthermore, the researcher kept a reflective diary throughout the data collection process. Some of these reflections are shared in Chapter 6.

Coherence means that the researcher must consider how readers will make sense of the researcher's interpretations. This ability to resonate with the readers is essential to the validity of a qualitative study (Shinebourne, 2011). The striving towards coherence was demonstrated by constant review and revision of the written analysis, findings, and interpretations in consultation with the research supervisors.

4.2.4.4 Impact and importance

The fourth criterion is impact and importance (Yardley, 2000). A study is deemed to have validity when it relates something of importance or can make an impact in a theoretical, social, or cultural manner. This impact can only be assessed in accordance with the objectives it was meant to address. In the current study, the objectives of the study are answered through the findings and interpretation of the findings of the experiences of the participants.

4.2.4.5 Transferability and empathy

Transferability stipulates that readers should be able to explore the findings of the study even beyond the context in which these findings are applicable (Willig, 2013). Empathy is a tool of observation used in qualitative research. The lens of empathy enables the researcher to utilise his/her own experience and intersubjective understanding of the society in which these participants live in the interpretation of the behaviour and conversation of the participants (Stiles, 1993).

4.3 Ethical regulations

Ethical clearance was obtained from the Faculty of Humanities' Research and Ethics Committee before commencing with the study (ref no. HUM037/0820). Furthermore, permission was obtained from Epilepsy SA to facilitate the recruitment of participants from their database (Appendix F). The organisation sent out an invitation to possible participants and those who were willing contacted the researcher directly. Ethical considerations in qualitative studies extend beyond this initial process of clearance and need to be implemented throughout the stages of data collection and analysis (Smith et al., 2009).

4.3.1 Informed consent

In qualitative research, informed consent extends beyond data collection, where participants are informed of the study and what to expect in the interview, to the possible outcomes of data analysis which may, for instance, include verbatim transcripts (Smith et al., 2009). The participants were fully informed of the aim and the methods of the study upon initial contact with the researcher. Participants were informed that their participation in the study was entirely voluntary and that they could withdraw from the study at any point without any consequences. Each participant had to provide written consent/assent (Appendix C and D) before any data could be collected (Willig, 2013). Since the study was conducted with minors, informed and written consent (Appendix A and C) had to be obtained by a parent or guardian as well as assent from the minor (Appendix B and D).

4.3.2 Avoidance of harm

In qualitative research, avoidance of harm is related to situations where sensitive issues are discussed that could invoke harm (Smith et al., 2009). With respect to the current study, the topic of living with epilepsy is a sensitive one and this must be combatted by appropriately phrasing questions to limit potential harm. The researcher took steps to make sure that the phrasing of interview questions and prompts limited any possible invoking of discomfort to the participant. Measures to minimise these risks also included a debriefing session after the interview, in which the participant was encouraged to ask any unanswered questions.

4.3.3 Psychological support

Participants were informed prior to the interview that should they feel overwhelmed or experience distress at any point during the research process, they were to disclose this to the researcher who would then refer them for psychological support to clinical psychologist Namrata Ranchhod (PR No. 8639302), who consented to providing free counselling sessions to participants, should this be required (Appendix G).

4.3.4 Confidentiality

A qualitative researcher can offer confidentiality, not anonymity. This is because the data will be seen, but can be manipulated to protect the identity of the participants (Smith et al., 2009). All participants were given pseudonyms to protect their identities when reporting on findings and quoting from the research. Interpretations of the research results were discussed with the participants when finalising data analysis to ensure that they felt protected from identification.

4.3.5 Privacy and storage of data

Upon completion of the interviews, recordings were immediately transferred to a secure email address. All data was password-protected immediately after the interview and throughout the transcription process. All transcribed data is free of any identifying features. The data was to be stored with the Department of Psychology for a period of 15 years in accordance with the requirements of the University of Pretoria. During this time, other researchers may have access to this data (which is anonymised) for use in future studies. Participants were made aware of this fact in the information sheet and informed consent.

4.4 Conclusion

This chapter outlined the methodology used in the current study and presented details of the study, from sampling, data collection, and data analysis, and also explored the ethical considerations of this study. In the next chapter, the findings of the study are shared and described together with verbatim statements from the transcripts.

CHAPTER 5: FINDINGS

This chapter presents the findings of the study. The chapter provides an introduction of each participant interviewed within their individual context as well as a brief description outlining the content of each interview. The themes that emerged from the IPA will be presented for each participant in table format. The emerging themes, subordinate themes and supporting verbatim statements from the respective interviews will be outlined in these tables. The researcher also provides a reflexive account of the interview process in each individual case. The chapter then moves on to a final table of themes drawn from all the interviews and the subordinate themes thereof. Each of the main themes identified are explored and identified through abstracts from the data. Finally, a conclusion on the results is provided.

5.1 Participants

The researcher conducted interviews with three participants. Although all three participants were recruited via Epilepsy SA, they differed from one another in context, experiences with epilepsy, and other lived experiences. As outlined in Chapter 4, the researcher utilised IPA to analyse the data collected through the one-on-one Zoom interviews. Through the data analysis, themes emerged from each individual interview, highlighting the richness and uniqueness of the participant's lived experience with epilepsy. Each participant was assigned a pseudonym to protect their identity, and to protect the confidentiality of the participant as discussed in the informed consent (Appendix A and B).

5.1.1 Participant X

Participant X is a 13-year-old girl in grade 7. Participant X was diagnosed with epilepsy in 2015 and was six years old at that point. Participant X's epilepsy initially presented with absent seizures, then transitioned into petit mal and grand mal seizures, and the current state of epilepsy is diagnosed as generalised epilepsy. The participant was interviewed via Zoom. During the interview the researcher experienced some difficulties with audio on both ends, which may have impacted the interview initially. The researcher was congruent with the participant, expressed gratitude to the participant for their patience regarding the technical issues, and finally was able to connect and proceed well with the interview. Participant X's mother was also present for most of the interview and provided some information with the participant. The mother shared her own insight throughout the interview process, along with Participant X. The researcher navigated through the interview by allowing the parent a say as well as addressing the participant for her view. The parent seemed well acquainted with and gave importance to the facts, dates, and number of seizures as well as hospital stays and check-ups. There was some inconsistency with the goals of the participant and those of the parents – the mother spoke of hers as well as the participant's father's wishes for the participant's future. Participant X is on medication and also follows a special keto diet in order to contain her seizures. The participant relies greatly on family support in the management of her epilepsy, especially on her mother. The parents are protective of the participant because of her epilepsy and have set many restrictions and rules with the intention of maintaining the participant's well-being and safety. Participant X discussed comorbidities such as heart problems, a connective tissue muscle problem, as well as issues of mental and emotional distress. The participant spoke of her experiences with bullying due to her epilepsy and due to her appearance as a result of a muscular disorder and also struggles with self-image. The participant also experienced issues regarding self-confidence and self-esteem. The participant was very active and energetic – she spoke in a fast-paced tone and moved around quite a bit during the interview. At the beginning of the interview the participant was hesitant to speak, but as the interview went along, spoke a lot more and was willing to be open and share details of her experiences with the researcher. The researcher continued to build rapport with the participant by probing and taking interest in the participant's goals, aspirations, fears, likes, and dislikes.

Table 1 contains the themes, subthemes, and verbatim statements that emerged from the IPA of participant X's interview transcript. Eight themes emerged from this transcript, namely cognition, anxieties, and emotional distress, coping and precautions, family role, comorbidities, treatment, aspirations, and transition of epilepsy into adolescence. These main themes were each further broken down into various subordinate themes.

Table 1

Themes and subordinate themes that emerged from the interview transcript of participant X

Participant X		
Main Themes	**Subordinate Themes**	**Verbatim Statements**
Cognition	Memory difficulties	*“So, when I get seizures, I forget a lot of stuff.”* *“And I'm very forgetful. I hate it and when my mom asked me something and I forget and I ask and my mom gets annoyed a lot. Because I forget stuff a lot.”* *“And I forget people’s names and it’s just…”*
	Academic difficulties	*“or a big thing so but people that are rich have to go there and it’s like 80 or 1000 or I don't know how much but it's a lot of money to go there.”* (When speaking about the money she would need to travel overseas). *“I’m the oldest one in this class.”*
	Empathy/emotional insights	*“I lost a lot of faith, actually…”* (When talking of experiences with bullying and untrue friends)” *“Last year I was in hospital for a week and that was a mission and we had to sleep with masks and there was a baby … it was very sad very sad every night I wake up and see how he sleeps his little nappy, well it was a big nappy but his so small. A little pump like n oxygen machine and that.”.*
Anxieties and emotional distress	Bullying	*“Like, I don’t have friends because they think I'm gonna infect them actually with it so. They're very scared”.* *“it's just embarrassing sometimes. And then the kids ask me how does it feel do you survive. What do you eat? Do you drink water? and how, do they put a spoon in your mouth. Do they put in your mouth to keep you alive? Like they asked me that question saying I get scared like it if it's gonna happen”* *“But in my old school, where my mom put me in, I get bullied a lot. So, I feel depressed a lot, because they say I'm fat, but I'm very skinny, and I'm built.”* *“But then they bullied me because of my image and call me that I’m tall. They say about my food but it's only way I can get better with my epilepsy, but they don’t care about me that’s why I have no friends, they hate me them don’t like me, they make fun of me, they go tell the teacher in big trouble a*

		lot, but (sigh) I deal with it. I'm the oldest one in this class, I have to take care of the little ones. But I have to deal with that". *"When I was 4 I was blind because I couldn't see so I had big glasses so they call me googly eyes and said I look like one that's why I tinted my glasses so they can't see my eyes so that's my dream to be like Harry Potter."* *"like with my stretchy skin and I have my second piercing and I color my hair and stuff. Some kids don't like me how I am now"* .
	Fear of death	*"Because I stopped breathing and mom and my dad are not there. Then I always think, am I gonna make it? Am I not gonna make it? My mind goes weird sometimes".* *"If I can grow… I don't know"* *"and everyone dies"*
	Self-identity	*"But then I don't want to look like Hulk that green little freaking thing but I wanna be myself but my legs are built a lot and it looks ginormous. And they think I look ugly. I don't know I just feel I don't look like myself. I was cute and funny but now I look like a monster. I don't know, I don't wear shorts a lot, I only wear jeans"* *"No, I'm not. I look like hulk".* *Parent: "she doesn't think a lot about herself. Her self-confidence hasn't been there."* *"Then they say you're not you I'm like right here. They don't like it I've got my piercing. I feel I look gorgeous, but no one likes it."*
	Epilepsy-specific fears and stressors	*"I wake up I hope I'm not getting seizures".* *"my grandma, my grandpa passed away of epilepsy so then it came to my mom and then me it goes very difficult for me actually because my sister also has epilepsy."* *"I actually don't like it because then I wonder all the time. Like, what happened to my grandma and my grandpa because I never meet then actually"* *"I just hate when someone talks about epilepsy. In my mind, it feels like I'm inside out I feel deep in a black hole like I don't like, like a lot"* *"But I get bad dreams about epilepsy all the time. Then I start crying."*

		"I get so tired and then stuff so I'm scared of water a lot, because of my epilepsy." *"But if people push me and say you can but I am scared of a lot of water so that's why I can't even bath because I'm scared of that. So, I just shower but water I'm scared of."* *"I wouldn't survive that. Agh what did I say. I can't survive it. It's hard so if someone screams all that stuff, it's just, I get it a lot."* Parent: *"I have my oldest daughter as well. Financially, not we just cannot do it."*
	Anger	*"I have to just keep calm because I have anger issues. If something falls and even breaks, I scream. I don't know what to do. But I have anger a lot. No patience with anything".* *"It just gets worse and screaming and shouting and all that stuff".* *"and I get moody a lot."* *"I handle the screaming and I get frustrated and scared and I get panic attacks. And then the teacher says No, nothing's going on. She's alright, then nothing gets solved. It just gets worse."*
	Quarantine	*"I can't go anywhere because of COVID am I willing to sleep over."* *"Oh worse this is something else. I stress a lot like I overthink stuff like a lot. Like I think of like last year what's gonna happen next year and all that kind of stuff all the time. I flashback all the time."* *"…these past few weeks online school that's why I even got a seizure in school like 100 or 400 pages every two weeks and like my reports and all that stuff was bad like 70 80 Not even gone to 100."* *"And sadly my mum couldn't even come visit me…"* (in the hospital)

Coping and precautions	Diet	*“ So, I get very hungry a lot and I eat like a cookie monster.”* *“I think I can control it. If I can go on this keto for two years, I think I can go out like with friends shopping but for now I can't do it. Because I'm scared. I'll just get all caught up”*
	Sleep	*“I'm like a sloth I just sleep a lot so then at night I sleep a lot”* *“It doesn't help us. Sleep only helps.”*
	Restrictions	Parent: “*it's her freedom. Because we do not let her sleep out. We do not let her go play with friends at their homes. Friends has to come to our house I think, ...freedom because she also she doesn't sleep on her own I sleep with her every night”.* *“I'm not allowed to even bath. I only shower and then my mom stays with me, so.”* *“but I can’t work with pasta yet because I’m scared I’m going to burn and they say with epilepsy you can’t work on a stove. I’m very careful. But my mum says I cannot be alone in the kitchen because my mom is scared”*
Family role	Parental Support	*“I wake up and my mom makes me nice, delicious food”* Parent: “*she also she doesn't sleep on her own I sleep with her every night”.* *“We constantly have that fear of something happening to her and we're not there especially after in the swimming pool”.* *“I spend time with my mom and my dad keeps off my mind and watch with my mom movies”*
	Differentiation from parental views	*“I'm not gonna do it… swimming is not my thing. Like, I know I swim good, like I just did it for my joints but now,”* *Parent: “So her dad and I have this big Olympic dream for her which you can hear is nothing out of the mouth about that”.*

		Parent: "*Daddy is the pushy one, mommy motivates in a nice." "…way, using the psychology in a way, what that always say, is the one that you will do this, you will do that, but I still try other ways and avenues.."* *"But that does not work"*
Comorbidities	Muscle condition	*"my I started swimming because of my joints. So now I'm a good swimmer."* *"If I bump something like I bruise and it burns my muscles."* *"And I'm very clumsy as well, like I'm very clumsy. Sometimes I fall and I bump my head or I bump my elbow and it clicks out. It's very annoying actually it happens a lot. Very annoying, then it dislocates."* Parent:*" she has ellen de- the mobility syndrome as well"* Parent: "*that's why she started swimming to build muscle around it to keep her joints in place because they it's not like a normal person's joints she's got thick skin and as she said when she bumps herself she gets lots of bruising..".*
	ADHD	*"I just play outside but I'm very active. Okay, maybe because I have ADHD."* *"Yes. We also have animals but they're two birds in one's."* (Starts a new topic out of the blue) *"Stuff I can't do the splits but can do one thing. You want to see?"*
	Heart problems	*"Then I get heart issues, I have heart issues too and my heart pains and it feels like I'm having a heart attack. And EEGs is also the worst. The things you put on your chest."*
Treatment	Medical treatment	*"She has been on Serontin epilepsy syrup. And she's also on Lamotrigine that was added after the grand mal seizures started"*
	Diet	*"but that on its own wasn't enough"* (referring to the medication) *"since Wednesday she is 3 months seizure free because we not cheating, we're strict about it. I make all her food we have a very special doctor that oversees the diet."* *"Like I don't cheat well I cheated a few times, but I was lucky"*

		“Coz ketos my only life to change actually”
	Support needed	Parent: “*She does have a psychiatrist but she's in need of a psychologist so that she can speak to someone. I mean, I can only do so much.”*
Aspirations	Future goals	*“I want to be an actress”* *“My dream is to be an actress, like bring in loads of money, go overseas and do whatever I want to there. Bring my family here and take care of them. It was my big dream.”* *“there I'm going to have to send money here for them to take care of themselves.”* *“My dream is always to go to Paris that was my big dream since I was small to go there to go travel that's my favorite kind of country”* *“Well, I think when I hope my epilepsy is not going to , you know, affect there’s like flashing lights but not that bad lights. That's not the things that I'll tell them”*
Transition of epilepsy into adolescence		Parent: “*That was when it went over to grant mal. Yeah before, it was only absent seizures”* *“She started with her period last year. And then she had her very first grand mal seizure.”*

5.1.2 Participant Y

Participant Y is a 16-year-old girl in grade 11. She was diagnosed with epilepsy when she was in grade 1 and this was also the last time she experienced a seizure, 10 years ago. She lives with her family – her mom, dad, and siblings. She was interviewed via Zoom and the researcher experienced some technical difficulties during the virtual interview, which made developing rapport take a little longer. However, rapport was developed by relating to the participant and checking in on how the participant was doing and if there were any questions or uncertainties that needed clarity from the side of the participant before starting the interview. Participant Y seemed unbothered by the diagnosis but felt that her epilepsy had impacted her memory quite a lot. This impact affected her daily life; as a student she found it difficult to remember content and memorise work for tests. It also impacted her in simple things such as forgetting what she needed to buy from the shops, people’s names, and so forth. The participant’s memory difficulties had a great impact on her self-esteem, confidence, and self-identity. She appeared to not be too bothered by her epilepsy, came across as indifferent, yet said she was grateful she no longer had symptoms as she didn’t want to be different. The participant was open about her epilepsy, so that the people around her knew that they should do something should she experience a seizure. She had a fear of having a seizure in public and that the people around her would not know what to do. Participant Y described her hospital experience when she had her last known seizure in grade 1, as a near death one and said she was afraid to die. Despite her fears, she is driven and ambitious and wants to pursue a career and help others. She spoke very passionately about not having the psychological support available that she needed and she wanted to be there for children. The participant went on and identified this absolute lack of support resources, saying they were expensive and out of reach. She identified teachers as lacking empathy regarding what she was going through. The participant explained that she dealt with her difficulties with an outlook of indifference; however, used emotive language at times in the interview that contrasted her approach. Her description and experiences of memory difficulties was congruent with her speech. Participant Y was on prescribed medication until grade 4 and then stopped. The absence of seizures was taken to mean that the epilepsy had settled, and the family dealt with the epilepsy by not dealing with it. The participant was still curious about her health and would have liked to visit her doctor to make sure she was as well as everyone assumed. The memory difficulties/challenges affected her “all the time”, especially being a student and memory being essential. She considered epilepsy as something you had and not something that you are. Participant Y was aware of her repetition of the issue of memory loss and mentioned that this had a huge impact on her. The participant experienced moments of low mood and a severe drop in self-confidence and has adopted an attitude of “it’s not my fault and there’s nothing I can do about it” as a means of life and coping. Participant Y was curious about her condition, she knew isolated things, like her brain being damaged with the seizures and one side had more cells than the other. She identified her essentials as her cellphone and her mother. She reported them as a list and did not go into more detail about her mom. The participant reported not attaining much help from the organisations – not much information or support. The feeling of needing support emerged when she spoke of this lack. The problems at school had influenced the participant’s goals and pursuits. She is driven, has dreams and is willing to struggle to achieve her goals and dreams. She repeatedly stated that she just needs to “co-exist” right now, with school and her issues there, teachers and them not understanding her. She spoke with great passion and excitement of the future, of children, teenagers – perhaps to be the support and help she never had. She expressed the biggest need as having someone to sit and talk to – and described a scenario that could help. She said she required a break; a focus on psychological help. The participant made mention of inner conflicts, but was hesitant to share more. The researcher acknowledged the probing at wanting to know if the label of epilepsy meant anything, and this may have steered the interview or influenced the participant's answers in some way. The questions is whether this was perhaps a little directive? The researcher did try to develop rapport by displaying empathy, unconditional positive regard, and congruence in interviewing style and tone of voice as well as non-verbal cues.

Table 2 contains the themes, subthemes, and verbatim statements that emerged from the IPA of participant Y's interview transcript. Six themes emerged from this data transcript: memory difficulties, anxieties and emotional distress, coping, comorbidities, emotional insight and awareness, treatment, rehabilitation, and support, and aspirations. These main themes were each further broken down into various subordinate themes.

Table 2

Themes and subordinate themes that emerged from the interview transcript of participant Y

Participant Y		
Main Themes	**Subordinate Themes**	**Verbatim Statements**
Memory difficulties	Impact on academics	*"So like most of the time, not some of the time, and most of the time I forget everything like I'll sit in class, with the work with the teacher and everything. Then immediately when I get out of the class, I forget the whole lesson."* *"Then I told him I was like, I tried I really tried with my memory is very bad and I have epilepsy. And he goes well that is not a excuse."* *"At some point, I wanted to study IT. Okay. But I didn't I wasn't doing well in maths, like the memory loss and understanding of maths, I don't know. No, I couldn't. I couldn't,"* *"because now you want to do something, but you are being prevented from doing something because of an illness that you have"*
	Difficulty remembering words/terms	*"Like, who did the test? I forgot what it's called. But it's like a machine of like a bed and like the brown thingy, that machine we went for that."*
	Impact on daily life	*"Now, maybe if you send me to go get by two by three items, I'll remember the two and then forget the third."* *"I don't remember most of my childhood. Because of like the seizures and stuff like that. So the only thing I remember is getting to school, and going home or going to school, and then all of a sudden, all of a sudden I'm at home."* *"I can't even remember someone's name, or to go fetch something someone asked me to go fetch you know things like that. It's like, I remember that I forget the small things."*
	Academic stresses	*"Especially, memory is very essential when it comes to like being a student and stuff like that."* *"That is the one thing that it affects negatively the most because it's important for me to remember my*

Anxieties and emotional distress		*schoolwork so if I don't remember my schoolwork, that's a big problem because tests are coming in all those different things”*
	Fears	*“I think the only thing that I can say that is sometimes I have a fear of like, do you know, when you have epilepsy and then you're afraid if you go somewhere, and then you have your seizure in front of people who don't even understand what to do.”* *“I don't want to be in a situation, you know, and be one of those people who are labeled as being different from everyone. I don't want that. Yeah”* . *“Because if I look at it wasn't diagnosed if the person the paramedics guy didn't come, and I really would have died.”*
	Self-identity	*“So if I don't remember I don't want to go to school, I don't want to participate, you know, things like that. It's, it obviously lowers your self-esteem and builds up your anger, because now, it's not your fault.”* *“now you start to believe the negative things that people say about you, about your memory loss and things like that. People saying it's just an excuse and stuff like that”* .
	Depressive thoughts	*“Yeah, sometimes I just feed into you go into it. You go into like this depressive state. You start as the thinking bad things about myself and all those different things and start believing and telling myself that what they're saying is true. You know, just that. And then after that, I realized, you know, that is not your fault. Move on.”* *“I think right now I'm in grade 11 so there's a lot of baggage that comes with it so just school and obviously me having my depression and stuff still trying to figure that out.”*
	Inner conflicts	*“that's besides epilepsy get yeah I think those are the only struggles that I have an inner what is that inner conflicts and stuff my own personal things and stuff like that”*
	Quarantine	*“like quarantine and stuff is a big struggle because there's work that we need to do and if the teachers don't give us right now we have to go back to school we have to catch up with that work …* *“And yeah, it's a lot of stress, it’s a lot of stress.”*
	Accepting of diagnosis	*“I say I have epilepsy they go oh okay fine. it's no, oh, my God, I'm so sorry. You know, it's just a normal reaction.”*
	Sense of control	*“That's why I always make sure that if I go to a new school, I'm friends with someone, I tell them, Hey, I have*

Coping		*epilepsy. So if something does happen one day, just know that I have epilepsy so, try and find help."* *"I don't want to end up having a seizure in front of someone that they don't know what's going on."* *"now that as I grow older, it just, it just comes to mind that Oh, you have epilepsy don't... make sure that at least you're someone close to you who's always with me know that you have epilepsy just in case something does happen."*
	Indifference	*"... and life goes on"* *"Honestly I don't tell myself anything hey. I just, if it happens, it happens."* *"Since it's been a while since I've had a seizure. I don't think anyone takes it serious. I don't even think I take it serious most of the time."* *"So we just move on with life as if I don't even have epilepsy, which I'm okay with that."* *"So yeah, you you move on. You can't really do anything about it. So yeah, yeah."* *"Right now I'm just I'm trying to find ways to co-exist with my memory loss try and find ways to I don't know just coexist find ways to be able to remember certain things I don't know just find ways to coexist with my memory loss. School wise I'm also learning to just coexist with school, with teachers."*
	Helplessness	*"And you can't do anything about it. You know?"* *"Try and do something about it if you can you know something like that. But otherwise, yeah, just let it pass. There's nothing you can do about it that's all you can do is just let it pass. And let (unclear). Because, unfortunately, whatever happens and something happens, you have to move on, you know, you can't stay in the same place and be depressed. Like I just let it pass and move on."*
	Family	*"my mom, my mom is a very huge support system. Because she was there through the seizures and obviously through my teenage years and everything that's happened."*
Emotional insight and awareness	Impact of Memory impairment	*"It's very bad. But yeah, it's very bad. And like I said, it's very essential to have good, if not a proper memory, like as a student, so yeah, it's very bad. Very bad."*
	Feeling misunderstood	*"The biggest problem with is, you know, when someone has never been in your shoes, so they don't understand where you're coming from."*

		“teachers stress me out because now I have my memory loss right and like the teachers have certain expectations about how learners are supposed to be. If you’re not in their expectation level whatever, you’re regarded as stupid or you don’t want to be here and all those different things.”
	Empathy	*“Yeah, it's a lot of stress. At the same time I understand where he's coming from… I can't remember, a monologue. Like it's you know if you get what I'm saying? Yeah, so yeah, but at the same time I understand where he's coming from so yeah.”*
	Awareness of self	*“I make reference to this a lot, because it impacts my life a lot.”* *“there's very limited resources for young people nowadays. And even if there is help, it's very hard to get the help that you need.”* *“I sometimes do because I want to know like what is going on in my brain is when they diagnosed epilepsy they say some brain... I think he said that some of the brain was like getting damaged and stuff like that I don't know.”*
Treatment, rehabilitation, and support	Medical treatment	*“Then from grade 4 I stopped medication. After that, I didn't get any sort of treatment. I stopped treatment completely.”* *“It was only medical treatment.”*
	Social support	*“Yes, I did. come across. Some who did, but I didn't directly contact them Yeah, I just saw from post and stuff.…”* (when speaking about seeing others with the same diagnosis on social media)
	Lack of support/ need for psychological support	*“I’ve noticed if you need help as a teenager you go through like struggles to get that help and no one has to struggle to get help.”* *“There are times where I wish that I could get help but first of all you need the money to get help.”* *“My… my biggest thing honestly would … just go to see someone sit down and talk.”*
Aspirations	Future goals	*“So, I want to do psychology because first of all, I do love psychology. And then, besides that, I want to do clinical psychology, clinical psychology of young people. And then besides that, my big big passion is fine arts. Okay, fine art. And I love theatre like, I have a lot of things that I love and that's the problem. I can't go study.*

		I love theater, I love fine art, and music. Those are the four things that I love." *"my memory loss has like a very big impact when it comes to my education in general. So when I do go back school, I study psychology or fine arts or drama, or wherever I study its obviously have an impact, but because I love those things, honestly. I don't care. I'm willing to take the risk"* *"I'm excited, I'm excited for them. But at the same time, I'm obviously scared because of the school part of things, obviously "…* (When speaking about the future) *"I'm just excited what the future holds for me".* *"I love children. I really, really love them and I'm young I live with young people and I go to school with young people and I'm a person who easily relates with people… it inspires me to one day want because I have this drive to I get to understand where they come from, listen to their stories and stuff like that.* *Because I have this drive that I want to help people in some way."* *"I don't want someone to struggle to get help. I would rather be able to help them without them having to struggle to get it because you struggle already why struggle more to get help that you need?"*

5.1.3 Participant Z

Participant Z is a 15-year-old girl living in a children's home. The participant was recruited via Epilepsy SA who reached out to the NPO at which a social worker identified and referred the participant. The social worker at the NPO also helped facilitate the interview via Zoom. The researcher attempted to develop rapport by asking the participant if she knew what the interview was about, if she was willing to take part, and if she had any questions or concerns. Participant Z had a vague idea, but was aware they were referred because they were living with epilepsy. The researcher observed when conversing with the participant that the participant's speech was slow-paced, she took some time to respond to questions, responded with one-word answers without any further elaboration, required a lot of probing, and required the question to be rephrased or split up in order to fully comprehend what was being asked. These noted difficulties were later confirmed with the social worker who is in contact with the participant. The participant is currently in grade 5. Participant Z is aware of the diagnosis of epilepsy and has to take medication on a daily basis. She also makes mention of a doctor telling her of the epilepsy and that this took place at a clinic;

this could be referring to the assessment at the children's home or perhaps in her previous home. The participant was able to spell their name and surname, but was, however, uncertain of other details, such as the type of epilepsy, when a diagnosis took place, and so forth. The participant gave assent and consent was given by the social worker as her guardian. The researcher took time to explain the interview process to the participant and asked if she had any questions. The participant was able to answer in concrete terms but struggled with abstract concepts. The participant associated seizures with the physical symptom of "falling". In this scenario, falling constitutes the experience. The participant remembered a doctor telling her about her epilepsy when she was very small. There is an indication that the seizures were under control as the participant said, "I'm no more falling every day." The participant indicated that the last seizure she had experienced was around three months back. The incident took place in school and the participant described it as, "I just fall." The teacher assisted the participant and after that she experienced headaches. The participant said that her friends did not know about the epilepsy, and it was only the social worker who knew, and she would be there if she needed anything. The participant answered in yes and no answers without elaborating further. Towards the end of the interview, when the participant was asked if there was anything she wanted to add, the participant made mention of something she struggled with – not being able to write Zulu but having the ambition to want to learn – and was continuously trying. The participant enjoyed school and learning, especially English, and mentioned being happy at school several times. The participant spoke about coming back from school and playing with her close friends every day, as well as receiving medicine morning and night from "the auntie" (the caretaker) on a daily basis – thus indicating some social interaction and a sense of community. The participant mentioned that although the caretakers gave her medication on a daily basis, she also remembered her medication herself. Lastly, the participant mentioned that her eyes were often red and itchy. The researcher noted that the participant was rather hesitant to speak and required probing; however, towards the end of the interview started volunteering information on her own, such as the want to learn to write Zulu and having itchy and red eyes every day.

The researcher then spoke with the social worker who provided some context. The social worker informed the researcher that the children's home was an NPO that took children aged 0 to 18. Participant Z had been in the children's home for 3 years. She used to live with her mother, but was removed due to abuse, sexual assault, and was found with burns on her skin. The participant was staying at the children’s home due to a court order. The social worker further disclosed that the participant struggled academically and said “She is struggling scholastically. And she is trying. We just waiting for her to be assessed by the Department of Education. However, she's on the list because she is 15 and she is behind with the grade.” This is referring to the list of children who needed to be assessed academically so that they could be placed in the suitable grade/schooling facility.

Participant Z was diagnosed with epilepsy when she came to live at the home 3 years before and started epilepsy medication which is administered daily by caregivers at the NPO. The social worker further informed the researcher that, “They always take her blood. Check it then they give her medication. So, I'm just not sure whether she's only on syrup or if she’s on the pill.” In cases of emergencies, these children are referred to a clinic or hospital nearby.

Table 3 contains the themes, subthemes, and verbatim statements that emerged from the IPA of participant Z’s interview transcript. Seven themes emerged from this data transcript, including cognitive difficulties, self-awareness, childhood, symptoms experienced, support system, treatment, and aspirations. These main themes where each further broken down into various subordinate themes.

Table 3

Themes and subordinate themes that emerged from the interview transcript of participant Z

Participant Z		
Main Themes	**Subordinate Themes**	**Verbatim Statements**
Cognitive difficulties		*"I have the.. the.. I don't know"* (when asked what type of epilepsy he has) *"Go to school and write when I come from school I feel happy."* *"We are writing. The teacher say we must make something we are making it. And then after we give it to the teacher."*
Self-awareness	Epilepsy	*"they're asking me that who's having the epilepsy."* *"Since I was born."* (when asked from when he had epilepsy) *"I started to feel sick. I was falling."* *"I'm no more falling everyday."* *"in the clinic… When I was small."*(when asked where she found out about her epilepsy). *"I'm having medication"*.
	Interests	*"I like writing and reading books."* *"I feel happy also at school."* *"English Maths… and life skills."* (Favorite subjects)
Childhood		*"She was staying home with a mother, but she was removed because of abuse. She was sexually assaulted. And then she had burns. So she, she was actually she removed herself because she admitted herself, she came with the transport with other kids who are also going to the same school with her. So that how her case that's how we received her. She's*

		here with a court order." (Reported by social worker.)
Symptoms experienced		*"I fall on the floor… When I wake up I was having a headache."* (describing the seizure she had at school) *"The eyes… They're red. And sometimes they get itchy."*
Support system	Caregivers and social workers	*"Only the social workers know* (about her epilepsy) *I do it when I come home."* (Referring to the children's home) *"Is the auntie*." (The caregiver who gives her medication)
	Teachers	*"It was the teacher…"* (who helped her after falling). *"She's a good teacher."*
	Friends	*"I'm playing… yes with my friend."*
Treatment	Medical treatment	*"I have night medication and morning."*
Aspirations	Future goals	*"is the Zulu Language… I can speak Zulu but I can't write it… I try and learn it."*

5.2 Data analysis: Final themes and subordinate themes

Table 4 contains the integrated themes and subordinate themes that emerged through IPA analysis across the data scripts. These themes are: mental health challenges, cognitive challenges, treatment, support, and coping, and emotional insights.

Table 4

Integrated themes and subordinate themes

Main Themes	Subordinate Themes
Mental health challenges	Self-identity
	Anxieties and fears
	Epilepsy-specific stressors
Cognitive challenges	Memory difficulties
	Academic difficulties
Treatment, support, and coping	Medical treatment
	Psychological support
	Family and social support
	Attitudes and outlooks on living with epilepsy
Emotional insights	Self-awareness and reflections
	Aspirations

5.2.1 Theme 1: Mental health challenges

The first theme that emerged from the data was one looking at the various mental health challenges experienced by the participants. This theme gives an in-depth look at the various types of challenges that were experienced by the participants and to what extent and how these challenges shaped the life of the participant. The researcher further clustered these challenges according to the subordinate themes of anxieties, fears, and epilepsy-specific stressors. A few of the subordinate themes are reflected by only some of the participants while others emerged in relation to all participants.

5.2.1.1 Self-identity

A major source of anxiety that emerged from the interviews with two of the three participants was centered on self-identity. There was a sense of longing to be oneself and of being accepted and, more importantly, being understood by peers and those around them. Participants shared several experiences highlighting this theme. Participant X experienced a great deal of bullying, in part due to her conditions of epilepsy and her muscular disorder, which had an impact on her appearance and physical stature. She said regarding the stigma around her epilepsy: *"Like, I don't have friends because they think I'm gonna infect them actually with it so. They're very scared. It's just embarrassing sometimes. And then the kids ask me how does it feel do you survive. What do you eat? Do you drink water? and how, do they put a spoon in your mouth. Do they put a spoon in your mouth to keep you alive? Like they asked me that question saying I get scared like it if it's gonna happen…"*. Participant X further described her perception of herself after training and taking up swimming (as a means of treating the muscular disorder) and how she now saw herself as *"the hulk"* and that she felt people thought she looks *"ugly"*. Participant X described herself as follows: *"I don't know I just feel I don't look like myself. I was cute and funny but now I look like a monster. I don't know, I don't wear shorts a lot, I only wear jeans"*. The participant's mother mentioned that her self-confidence was very low.

Participant Y linked her self-esteem to her challenges with memory which resulted in academic struggles and hence her poor view of herself. Participant Y explained: *"So if I don't remember I don't want to go to school, I don't want to participate, you know, things like that. It's, it obviously lowers your self-esteem and builds up your anger… now you start to believe the negative things that people say about you, about your memory loss and things like that. People saying it's just an excuse and stuff like that."* Participant Y described being misunderstood by teachers and peers and said they viewed her difficulties "*as an excuse",* and further talked about going into a *"depressive state."* Participant Y explained that *"you start as the thinking bad things about myself and all those different things and start believing and telling myself that what they're saying is true… teachers stress me out because now I have my memory loss right and like the teachers have certain expectations about how learners are supposed to be. If you're not in their expectation level whatever, you're regarded as stupid or you don't want to be here and all those different things."*

5.2.1.2 Anxieties and fears

Two of three participants described the fear of anticipating a potential seizure and they thought about this consciously on a daily basis. Participant X shared a daily thought, *"I wake up and I hope I'm not getting seizures"* while participant Y said, "*the only fear when you have epilepsy and then you're afraid if you go somewhere, and then you have your seizure in front of people who don't even understand what to do."* This fear impacted the social aspect, where these participants felt they need to always be in controlled environments (with people who knew of their epilepsy and would know how to help). This fear further escalated into a fear of death. Participant X made mention of this a few times in the interview; once when she said, *"Because I stopped breathing and mom and my dad are not there. Then I always think, am I gonna make it? Am I not gonna make it? My mind goes weird sometimes".* Participant X reported having lost family members who had also had epilepsy and she made the statement, *"and everyone dies."* Participant Y expressed feeling good that she was diagnosed, else she felt life would have been worse and had the paramedic not been there to help her when she experienced a seizure many years ago she recalled, *"if the person, the paramedics guy, didn't come, and I really would have died."*

Two of the three participants discussed the impact that being in quarantine (due to the Covid-19 pandemic) had on their lives and its contribution to their anxieties, specifically in terms of academics. Both participants spoke of the difficulties of having online classes and how this had contributed to a deficit in understanding of schoolwork, as there was no face-to-face teaching and thus, they struggled in their understanding of certain new concepts taught virtually. This, coupled with the fast-paced work schedule, had given rise to high stress levels. The participants described their experiences as follows: Participant X shared, *"these past few weeks online school that's why I even got a seizure in school like 100 or 400 pages every two weeks."* Participant Y reiterated this by repeating, *"it's a lot of stress, it's a lot of stress,"* when speaking about schoolwork during quarantine. Participant X further felt the impacts of Covid-19 restrictions when she was admitted to hospital as she describes it by saying, *"And sadly my mum couldn't even come visit me."*

5.2.1.3 Epilepsy-specific stressors

It is evident that the remembrance of having epilepsy is a constant in the life of each participant interviewed, be it through medication, recurring thoughts, or external impacts. The fear of anticipating a seizure to the point of having nightmares about having a seizure and the fear of having a seizure in front of someone who did not know what to do were explored thus creating anxieties around sleep and rest in addition to the waking hours of the day. The participants shared the following experiences: Participant X stated, *"But I get bad dreams about epilepsy all the time. Then I start crying."* Participant Y commented, *"now that as I grow older, it just, it just comes to mind that Oh, you have epilepsy don't... make sure that at least you're someone close to you who's always with me know that you have epilepsy just in case something does happen."*

Participant X reported having many family members, including a sister, also diagnosed with epilepsy and at the point where her mother spoke of these family members and their struggles, the participant responded, *"I just hate when someone talks about epilepsy. In my mind, it feels like I'm inside out I feel deep in a black hole like I don't like, like a lot."* Furthermore, participant X shared an incident where she experienced a seizure while she was swimming. This incident is described as highly significant in the participant's life and she reflected on the impact, *"I'm scared of water a lot, because of my epilepsy… I am scared of a lot of water so that's why I can't even bath because I'm scared of that. So, I just shower but water I'm scared of."*

5.2.2 Theme 2: Cognitive challenges

The second theme of cognitive challenges was a theme that was prominent with all of the participants. Though in varying degrees and contexts, the researcher was interested to see this theme appear in the life experiences of all the participants and how this theme contributed to their lives, with special importance to their current adolescent stage of life and the focus of school education that this stage of life brings with it. The subordinate themes identified under this theme are memory difficulties and academic difficulties, which, in some respects, overlap.

5.2.2.1 Memory difficulties

Memory difficulties were discovered to be a significant challenge for two of the three participants. Though tied to the next subtheme, academic difficulties, the theme was important enough to stand on its own as well. Participant Y explained that her difficulty with memory was the consequence of her epilepsy which she found impacted her daily life most, especially with regard to her academic life. In fact, this challenge is so impactful on a basic life level that she described her experience as follows: *"I can't even remember someone's name, or to go fetch something someone asked me to go fetch you know things like that. It's like, I remember that I forget the small things."* Participant Y further spoke about being unable to remember a lot of her childhood and that there were definite gaps in her memories. Another example she gave of her struggle with memory is, *"Now, maybe if you send me to go get by two by three items, I'll remember the two and then forget the third"*. The participant also struggled to remember terms during the interview and the distress her struggle with memory caused was evident in her descriptions of situations and how these strained her day-to-day life. Participant X mentioned that the onset of a seizure for her was coupled with forgetting, *"So, when I get seizures, I forget a lot of stuff… And I forget people's names"*. Later in the interview she once again made reference to forgetting and how this impacted her daily life, *"And I'm very forgetful. I hate it and when my mom asked me something and I forget and I ask and my mom gets annoyed a lot. Because I forget stuff a lot."*

5.2.2.2 Academic difficulties

Academic challenges are seen to exist to some extent in the life story of each of the participants. Participant X mentions, *"I'm the oldest one in this class,"* indicating a mismatch between the participant and the standard milestones of their peers. Participant X, however, did express receiving high marks, *"*70, 80, not even gone up to a 100,*"* when describing the difficulties with online schooling during Covid-19. Participant Y discussed her challenges with memory as something that had a massive impact on academic success and further remarked that *"memory is very essential when it comes to like being a student and stuff like that."* She reiterated this throughout the interview and described the situation as: *"That is the one thing that it affects negatively the most because it's important for me to remember my schoolwork so if I don't remember my schoolwork, that's a big problem because tests are coming in all those different things."*

Participant Y gave an example of how her memory impacted her school life: *"So, like most of the time, not some of the time, and most of the time I forget everything like I'll sit in class... then immediately when I get out of the class, I forget the whole lesson."* The participant also explained that she had to change from the courses she initially wanted to do (mathematics), because her marks were not high enough (according to the school's requirements to take those courses).

Participant Z is 15 years old and in grade 5. The social worker explained that the participant was yet to be assessed, then placed in the correct school setting – depending on her specific cognitive needs. The social worker also reported: *"she is struggling scholastically. And she is trying. We just waiting for her to be assessed by the Department of Education."*

5.2.3 Theme 3: Treatment, support, and coping

5.2.3.1 Medical treatment

All three of the participants reported being on medication at some time or the other since being diagnosed with epilepsy. Two of the three participants were still on medication, while one of the participants had discontinued the medication several years ago. The two participants currently on medication experienced this as a daily part of life. Participant X's mother disclosed that the participant had been on medication since her diagnosis and that the medication had changed as she grew older, and her epilepsy evolved (from absent seizures to grand mal seizures). Participant X further explained that the medication itself was not enough and that she was on a keto diet to help keep the seizures under control. The participant's mother explained, *"all her food we have a very special doctor that oversees the diet."*

Participant Z mentioned that she took medication on a daily basis and said: *"I have night medication and morning."* These medications are administered to Participant Z timely by the caretakers at the children's home. The social worker also added that Participant Z was diagnosed and was prescribed medication 3 years before, when she came to live at the children's home. She further added that the nursing staff were taking Participant Z's blood regularly and kept checking on her medication.

Participant Y, on the other hand, explained that she had initially taken medication but later discontinued the medication: *"Then from grade 4 I stopped medication. After that, I didn't get any sort of treatment. I stopped treatment completely."* Participant Y did indicate that the seizures had come under control and hence the medication was not needed. The participant also mentioned that someone had said that the medication had an impact on memory and therefore she didn’t want to continue with the medication.

5.2.3.2 Psychological support

A lack of psychological support was reported and an even bigger need for this gap to be filled was indicated in two of the three interviews. Participant Y, when asked about her treatment for epilepsy stated, *“It was only medical treatment.”* Participant Y then went on to share what she felt was lacking in terms of support, speaking of the needs of a teenager in general: *“I’ve noticed if you need help as a teenager you go through like struggles to get that help and no one has to struggle to get help”*. The participant also put her own needs forward when she said, *“There are times where I wish that I could get help but first of all you need the money to get help… My… my biggest thing honestly would … just go to see someone sit down and talk.”* Participant Y described the situation as a *“lack of resources”* and further explained that attaining mental health services was also financially difficult.

Participant X’s mother also explained the need for a psychologist. The mother explained: *“She does have a psychiatrist but she's in need of a psychologist so that she can speak to someone. I mean, I can only do so much.”* The participant’s mother also made mention of the financial difficulties of attaining mental health services. The participant weighed in and said it might help, but that she felt her father too needs therapy as he has the *“same issues”* as her (referring to her issues around anger).

5.2.3.3 Family and social support

Two of the participants made mention of the importance of family and the support of family in their lived experiences, especially with regard to the people they live with. These individuals had been through the life experiences with them thus creating a bond of shared understanding. Participant X described her life mainly with her parents and how they managed her epilepsy and were her source of comfort and strength. This bond can be seen in her statements: *“I wake up and my mom makes me nice, delicious food… I spend time with my mom and my dad keeps off my mind and watch with my mom movies”*. Furthermore, participant X’s mother (present for the interview) explained that both the mother and father were very protective of the participant and had certain rules and restrictions to ensure her well-being, such as, “*it's her freedom. Because we do not let* *her sleep out. We do not let her go play with friends at their homes. Friends has to come to our house…she also she doesn't sleep on her own I sleep with her every night".* Participant X further provided insight into the family role in her life: *"I'm not allowed to even bath. I only shower and then my mom stays with me… but I can't work with pasta yet because I'm scared I'm going to burn and they say with epilepsy you can't work on a stove. I'm very careful. But my mum says I cannot be alone in the kitchen because my mom is scared."*

The participant's mother mentioned that she (the mother) was part of a nationwide support group for epilepsy. The mother also mentioned that their doctor provided some support and guidance to the participant and the family and that the doctor had spoken to the participant several times via Zoom.

Participant Y described her relationship with her mother as an important one for her. *"My mom, my mom is a very huge support system. Because she was there through the seizures and obviously through my teenage years and everything that's happened."* Participant Y further described the role of her family with regard to her epilepsy as follows: *"Since it's been a while since I've had a seizure. I don't think anyone takes it serious. I don't even think I take it serious most of the time. I haven't had a seizure in a while. So we just move on with life as if I don't even have epilepsy, which I'm okay with that."* Participant Y mentioned that she did follow certain epilepsy-related pages on social media and reads comments on posts that were meaningful to her. She explained that she did not usually interact with the posts, but it was helpful to read comments and relate to people's experiences with epilepsy, and the participant commented, *"which is nice, because now you have people who you can relate to or people can relate to you."*

Participant Y shared that she reached out to an organisation in the hope to acquire more information on her epilepsy, but to no response. *"But after that, I didn't get any more information. No contact no nothing."*

Participant Z did not share the family aspect as the other two participants did; however, the social structure surrounding her consisted of the caretakers, medical staff, social workers, teachers and friends in and associated with the NPO in which she currently resides (the children's home). Participant Z spoke of the social workers as being the only ones who knew. *"Only the social workers know"* (about her epilepsy). When asked who administered her medication, Participant Z said, *"Is the auntie"* (the caregiver who gives her medication). The participant further expressed joy in attending school and said that her teacher helped her if she was *"falling"* at school. The participant also talked about playing with her friends every day when she comes back from school. *"I'm playing… yes with my friend."*

5.2.3.4 Attitudes and outlooks on living with epilepsy

Participant Y describes her family's coping style as *"I haven't had a seizure in a while. So we just move on with life as if I don't even have epilepsy, which I'm okay with that."* The participant said that this outlook worked for her: *"I don't want to be in a situation, you know, and be one of those people who are labeled as being different from everyone."* Participant Y also described her approach to struggles and said that sometimes there's nothing you can do about situations, and you simply need to *"let it pass"* and *"move on."* The participant shared the following: *"So yeah, you you move on. You can't really do anything about it."* Participant Y also talked about learning to "co-exist", as she shared the following: *"Right now I'm just I'm trying to find ways to co-exist with my memory loss try and find ways to I don't know just coexist find ways to be able to remember certain things I don't know just find ways to coexist with my memory loss. School wise I'm also learning to just coexist with school, with teachers."* Participant Y was also very honest and open about her diagnosis of epilepsy. She shared this with the people around her and felt it was no big deal; the participant does not fear any "label" and says, *"if you have epilepsy, you have epilepsy, it's fine"*.

5.2.4 Theme 4: Emotional insights

The fourth theme that emerged is one of emotional insights – each participant was reflective and thoughtful in what they discussed in the interview and these moments of insight intrigued me so much so that a theme of significance emerged. The participants also reflected on goals and aspirations for the future.

5.2.4.1 Self-awareness and reflections

Two of the three participants shared emotional reflections and insights as they discussed their life experiences. Participant X reflected on her experiences of being bullied at school and said, *"I lost a lot of faith, actually…"* The participant also relayed a story of her experience of being in hospital and her observations of a certain patient with whom she shared a room. She expressed her empathy and grief in regard to this baby she had formed a bond with. She relayed that, *"Last year I was in hospital for a week and that was a mission and we had to sleep with masks and there was a baby … it was very sad very sad every night I wake up and see how he sleeps his little nappy, well it was a big nappy but his so small. A little pump like n oxygen machine and that."* Participant X further shared her understanding of the class dynamics and the bullying where she said, *"I'm the oldest one in this class, I have to take care of the little ones. But I have to deal with that."*

Participant Y made mention of her struggles with her memory quite a few times throughout the interview and was reflective of this when she said, *"I make reference to this a lot, because it impacts my life a lot."* The participant further reflected on not feeling understood by teachers and peers, but also stated that she understood where they were coming from. *"The biggest problem with is, you know, when someone has never been in your shoes, so they don't understand where you're coming from… Yeah, it's a lot of stress. At the same time I understand where he's coming from… I can't remember, a monologue. Like it's you know if you get what I'm saying? Yeah, so yeah, but at the same time I understand where he's coming from so yeah."* Another reflection from Participant Y was her assessment of a lack of available resources for young people. In this regard she said, *"there's very limited resources for young people nowadays. And even if there is help, it's very hard to get the help that you need."*

5.2.4.2 Aspirations

Aspirations for the future was a theme that appeared across the interviews. Each participant had a dream that they were passionate about and wanted to see fulfilled. Participant Z explained that she can speak Zulu, but cannot write the language. She wants to be able to write in Zulu and is working on that goal in school. She said, *"the Zulu Language… I can speak Zulu but I can't write it… I try and learn it."* The social worker later expanded and said that participant Z was a very keen learner who was trying. This goal was mentioned randomly by the participant and seemed to be one of significance to her.

Participant Y, when asked about her aspirations said, *"So I want to do psychology because first of all, I do love psychology. And then, besides that, I want to do clinical psychology, clinical psychology of young people. And then besides that, my big big passion is fine arts. Okay, fine art.*

And I love theatre like, I have a lot of things that I love and that's the problem… I love theater, I love fine art, and music. Those are the four things that I love." The participant further expressed that *"I'm just excited what the future holds for me… But at the same time, I'm obviously scared because of the school part of things, obviously,"* (in relation to her memory struggles). The participant talked excitedly about her goals and why they were important to her. *"I love children… I have this drive to I get to understand where they come from, listen to their stories and stuff like that… Because I have this drive that I want to help people in some way… I don't want someone to struggle to get help."*

Participant X expressed her dream as, *"My dream is to be an actress, like bring in loads of money, go overseas and do whatever I want to there. Bring my family here and take care of them. It was my big dream…. My dream is always to go to Paris that was my big dream since I was small to go there to go travel that's my favorite kind of country."* The participant expressed her aspirations excitedly but did at a point mention a fear of her epilepsy hindering this dream. Yet, her aspirations were also not aligned with those of her parents who, her mother informed, had Olympic swimming dreams for her.

5.3 Conclusion

This chapter highlighted the themes and subthemes that emerged from the IPA of the three interview transcripts as well as substantiated verbatim statements supporting and creating these themes. An introduction to each participant as well as an overview of each interview was also provided. The themes and subordinate themes shed light on how uniquely and subjectively complex and layered the experiences of the different facets of life are for an adolescent living with epilepsy, and how context plays a role in these experiences. In the next chapter, the researcher will offer an in-depth discussion on the interpretation of these themes and provide personal insight and reflection on the research process and the findings of the study.

CHAPTER 6: DISCUSSION

In this concluding chapter, the findings of the study are discussed and interpreted. As the interpretations are explored, they are substantiated with existing literature to provide a fuller understanding of the lived experiences of the adolescents interviewed. An overview of context and of the transitional age of adolescence is given some consideration. The researcher includes inserts from a reflective diary that was kept throughout the research process at different sections within this chapter. The limitations of the study are then considered, together with recommended future studies. Finally, the personal insights of the researcher are reflected upon and the chapter is concluded.

6.1 The adolescent in context

The experiences of young people living with epilepsy are very likely to differ in various cultural contexts, socioeconomic status, and the living environment. Cultural norms and beliefs may influence the way in which epilepsy is perceived, the attitudes of society and family towards the individual, as well as treatment and coping strategies. These experiences influence how epilepsy is managed and this shapes the life of the individual living with epilepsy (Chew et al., 2019).

Chew et al. (2019) found that young people with epilepsy narrated a connection between their epilepsy and how it influenced their developmental tasks specific to adolescence, such as autonomy and independence, social development, and self-esteem – all of which are topics explored in the current study and identified as challenges for the adolescent. The study by Chew et al. (2019) further revealed that experiences differed across contexts; in western cultures, autonomy was deemed significant in the life of the young person with epilepsy in matters such as handling their own medicine schedules, while in Asian and African cultures this responsibility was fulfilled by parents or guardians.

It is important to take a step back and remember that the participants in this study should in the first place been seen as young adolescents before they are seen as persons with epilepsy. The challenges, emotions, social interactions, relationships, school life, and family life are all part of the normal developmental process in this life stage. Coping with all of these aspects within the context of a certain culture – a certain set of beliefs (about illnesses, treatment, and social functioning), values, and history (Chew et al., 2017) – as well as being diagnosed with and dealing with epilepsy is their backdrop for growing up.

Reflective Diary: Insert 1

I can't help but reflect on the developmental stages of these adolescents. Adolescence marks the stage of increased autonomy (Erikson) which becomes a challenge in the life of an adolescent with a chronic illness, and understandably so.

6.2 Discussion of themes

The aim of this study was to explore the experiences of adolescents living with epilepsy in South Africa. The objectives of this study were to explore from the adolescent's perspective the social, psychological, neurobiological, and cognitive implications of living with epilepsy, to explore the world view of the adolescent participants with epilepsy, and to explore and describe the challenges faced by adolescents living with epilepsy. Keeping the aim and objectives in mind, four main themes and 11 subordinate themes were identified during the analysis stage of the study and presented in Chapter 5 (Table 3). In this section, these themes are further discussed and incorporated with the literature, together with the researcher's interpretations of the themes. The themes and sub-themes are discussed in the same order as they were presented in Chapter 5.

6.2.1 Theme 1: Mental health challenges

Mental health challenges were seen to be significant experiences in the findings of this study. It also becomes evident through the current study that mental health challenges can take many different forms and exist in different contexts in the life of an adolescent living with epilepsy in South Africa.

6.2.1.1 Self-identity

Self-identity was found to be a source of stress and a contributor to challenges in the lives of the adolescent participants living with epilepsy. It also became clear that discovering one's identity and sense of self is a process of growth and experience. Self-identity is constructed from within the individual and also from what happens around the individual. This ties in with the literature, as Kilinc et al. (2018) reported that living with a chronic condition causes strain on one's sense of self and that in some ways, having such a condition compels one to reconstruct their identity in a way that accommodates their condition. The findings in this study are based on the experiences of adolescence – a developmental stage in respect of which Erikson (1968) theorised that the self-image of the adolescent undergoes modifications consistently; thus it is not the reconstruction, but rather the construction of their initial identity to begin with. The literature further suggests that there is a negative impact on the self-esteem, and self-concept of children living with epilepsy – consistent with this study's findings. Admi and Shaham (2007) found that adolescents did not view epilepsy as the center of their lives, and did not perceive themselves as ill, but were merely living and coping with a condition, barely affected by seizures. A more recent study conducted by Eastman (2019) also revealed that some participants viewed their epilepsy as manageable and did not allow it to control their lives. This, while consistent with some of the findings, contradicts some other parts of the findings, as some participants reported that their condition dictates the structure of their lives.

In the current study, participants reported that their peers viewed their epilepsy as contagious and frightening, and they often felt rejected by others because of this. A study conducted by Hosseini et al. (2013) revealed that persons with epilepsy often encountered public responses of stereotyping, social stigma, and being labeled as psychotic, mad, and possessed. This discrimination often left these individuals feeling less competent, isolated, rejected and they ultimately experienced a loss in identity which interfered with their daily lives (Hosseini et al., 2013). Another study (Kirabira et al., 2020) found that children with epilepsy experienced a high level of perceived stigma in school and that the misconception of the community was that epilepsy was contagious. Increased stigmatisation in school led to poor self-esteem, absenteeism from school, and thus poor overall academic achievement (Kirabira et al., 2020) .

6.2.1.2 Anxieties and fears

Existing research depicted that children and adolescents with epilepsy are at a high risk of developing psychiatric comorbidities of anxiety and depression which are seldom identified and often left untreated (Mameniškienė et al., 2017; Puka et al., 2017). Furthermore, people with epilepsy are likely to exhibit clinically significant levels of anxiety, especially in the form of excessive worrying about having a seizure, the element of unpredictability of when the seizure would occur in particular, and poor emotional well-being (Geerlings et al., 2015). Anxiety disorders are prevalent in 16% to 50% of children and adolescents with epilepsy and have a negative impact on the quality of life of these children and adolescents (Stefanidou et al., 2020). Findings from the current study align with these findings as it was found that anxiety and preoccupation with the occurrence of seizures were challenges that the participants went through, some on a daily basis. Levels of anxiety were narrated by the participants as being high. In fact, the fear of experiencing a seizure was reported to be a significant and consuming one. Previous research suggested that the fear experienced was more than just worrying about when a seizure will occur; it also encompassed a fear of negative responses from those around them (Ryan & Räisänen, 2012) and a deep-rooted fear of the unknown – the unpredictable nature of a seizure, sometimes coupled with the inability to breathe, memory loss, and essentially a loss of control. A study conducted by Geerlings et al. (2015) identified levels of distress in persons with epilepsy to be comparable to those of people with mental health problems.

6.2.1.3 Epilepsy-specific stressors

According to the literature, adolescents deal with a lot of challenges and stressors in daily life and adolescents who live with a chronic disease, such as epilepsy, have additional demands to manage, which results in a more stressful environment for these young people and their families compared to those adolescents who do not live with a chronic disorder (Chew et al., 2019). Previous research also concurred that persons diagnosed with epilepsy have a high risk of developing depression (Danzer, 2012). Factors such as the unpredictable nature of seizures, inability to control seizures, perceived social stigma as well as financial strain could increase the risk of developing depression in these individuals (Stefanidou et al., 2020). In the current study, some participants described themselves as feeling depressed at certain times. These feelings were expressed in correlation with academic stress, personal relationships, limits on social interaction, feeling misunderstood, as well as with having epilepsy and the fear of anticipating seizures. It is significant to note that these feelings are the feelings of adolescents and reflect the challenges that adolescents go through (Stefanidou et al., 2020), but are also coupled with the challenges that come with living with epilepsy. Participants also identified financial struggles when acquiring mental and medical healthcare and described how this contributed to their distress.

The literature informed that adolescents with epilepsy feel discriminated against in their schools (Eklund & Sivberg, 2003) and this is consistent with some of the research findings in this study. The participants believed that their stressors were linked to their epilepsy, including seizures, limitations on social activities, side effects of the medication, and feeling that they are different to others (Eklund & Sivberg, 2003). Although the study was conducted by Eklund and Sivberg (2003) almost two decades ago, the participants in the current study still experienced these stressors and therefore it seems to still be relevant.

Misconceptions about epilepsy are still prevalent in Central Africa and in other areas across the world, both rural and urban (Adjei et al., 2018; Hosseini et al., 2013). People still view epilepsy as supernatural and contagious (Kirabira et al., 2020). These cultural beliefs may elicit negative attitudes from society and result in the stereotyping of persons with epilepsy. The stigma surrounding epilepsy is still seen to be prominent in our society (Adjei et al., 2018; Mbelesso et al., 2019). Findings from the current study confirmed that these misconceptions exist even today. A participant reports bullying in school for having epilepsy and children keeping their distance out of fear of the contagious nature of epilepsy. These findings highlight the need for more social awareness and educational interventions about epilepsy and other conditions.

6.2.2 Theme 2: Cognitive challenges

The findings of the current study report that cognitive challenges are a real struggle in the lived experiences of the adolescents with epilepsy. This makes sense in the context of an adolescent whose current stage of life is centered around school and social development. Participants expressed memory difficulties as well as cognitive challenges with schoolwork. The findings express these difficulties as a reoccurring theme throughout the interviews, thus reiterating their significance in the lives of the participants. It is estimated that 80% of persons with epilepsy also have a behavioural disorder and/or some kind of cognitive impairment (Chong et al., 2016).

6.2.2.1 Memory difficulties

The study revealed the difficulties that participants face in daily life with regard to memory. There was mention of forgetting everyday things and the frustration and loss of control that comes with this forgetting. Certain participants reported having blanks in their childhood memories, and missing chunks of life stories that need to be told to them by others. Another participant narrated daily experiences of forgetting what was said in class or a list of things to buy, inducing frustration from the individual and from those around them. This difficulty with memory was reported to have an influence on the next subtheme to be discussed, regarding academic challenges. Parallel to the findings of this study, it is reported that specific epilepsies cause verbal and non-verbal dysfunction in learning and memory, especially in adolescents and young adults with epilepsy (Engel et al., 2019).

6.2.2.2 Academic difficulties

Studies conducted by Kirabira et al. (2020) at a school in South-Western Uganda and by Wo et al. (2018) in Kuala Lumpur, Malaysia, both found that children with epilepsy showed poorer overall academic performance. According to another study carried out by Chong et al. (2016), children with epilepsy experienced cognitive difficulties, memory struggles, and attention problems, which caused them to feel “slower” and less competent compared to their classmates. In line with Chong et al.’s (2016) research, the current study also indicated cognitive difficulties in the adolescents with epilepsy. The findings revealed that the participants struggled with schoolwork, had difficulty with concentration, and experienced memory difficulties.

Looking a little deeper, it is more than just not doing well or not remembering a few things that disrupts the lives of these individuals; it is the depth and concern with which these experiences were related by the participants. It is also the discussion of how these difficulties contribute to their lived experiences in the form of stressors and anxieties, as well as the fear of negative responses from others, and ultimately a fear of not being able to achieve their goals due to poor academic performance.

6.2.3 Theme 3: Treatment, support, and coping

Research states that transitional problems occur in many aspects in the life of an adolescent with epilepsy. The adolescent requires support medically and non-medically –psychologically, socially, and emotionally – to make the transition from childhood epilepsy to adult epilepsy and this makes the time of adolescence complex (Geerlings et al., 2015). The findings of the current study can attest to this complexity and can shed some light on the expressed needs of these adolescents who report needing social and psychological support. The adolescents also shared that in their experience, limited resources were found, especially regarding psychological resources.

6.2.3.1 Medical treatment

Research showed that most children with epilepsy had sufficient knowledge of their medication and the times they were supposed to take said medication (Pauschek et al., 2016), as was also found in the current study. They did not, however, take the medicines themselves, but it was rather administered to them by a parent or guardian. The study also highlighted that some participants used medicines after being diagnosed, but at some point discontinued the usage. Some findings from the current study suggested that this could be due to experienced or researched side effects of the medicine.

Childhood-onset epilepsy is reported to be diverse, complex, and occurs in conjunction with many comorbidities (Geerlings et al., 2015). These finding correlate with the findings of the current study, as it was found that some of the participants experienced several other medical conditions and psychological difficulties in conjunction with epilepsy. It is interesting to reflect on whether these comorbidities were in fact the primary difficulties that these adolescents faced, causing their symptomology – the cognitive difficulties, psychological challenges and so forth – or whether the epilepsy was in fact the primary difficulty.

6.2.3.2 Psychological support

The findings of this study revealed that psychological support is much needed, and the need is overtly expressed by the participants. The lack of availability of such resources due to financial situations and even lack of accessibility was also reported. According to Geerlings et al. (2015), psychological support is essential to prevent long-term seizure conditions and it is vital that psychological support be easily accessible.

A study conducted by Henning et al. (2019) reported that while persons with epilepsy could easily find access to information on medical treatment for epilepsy, they struggled to find nonmedical support such as psychological support and social support for epilepsy. Children and adults with epilepsy experience difficulties with acquiring mental healthcare due to a lack of availability and accessibility, as well as a lack of mental health practitioners who understand the specific mental health considerations related to epilepsy (Stefanidou et al., 2020). This is consistent with what was found in the current study. Participants experienced psychological resources as limited and even when they reached out to epilepsy-related institutions with certain questions on the internet or on social media, they experienced little to no feedback. In South Africa, there is an absence of any child and adolescent mental health policy and a general neglect of mental healthcare for children and adolescents, despite the fact that almost 40% of South Africans are under the age of 18 years (Mokitimi et al., 2018).

Reflective Diary: Insert 2

It is startling to me that mental health services are so lacking and at the same time so needed. I feel this is an important aspect to report on, being from the background that I am. This is an important lack to highlight. Interventions are needed.

6.2.3.3 Family and social support

Studies (Chew et al., 2017; Engel et al., 2019) suggest that children with epilepsy gain independence and self-management at a later stage than children without epilepsy. This transition into adulthood depends more on gaining developmental maturity than about the child's age (Geerlings et al., 2015). Self-efficacy in terms of managing their own chronic illness is significant in the developmentally transitional phase of epilepsy. Such attaining of self-efficacy may, however, prove challenging in the life of an adolescent with epilepsy, considering the limitations they experience with social aspects (Engel et al., 2019). In the current study it was found that there is still a lot of dependency on parents/guardians when it comes to medicine administration, limits on social interactions, and so forth. It is fair to say that caregivers are concerned for the safety of the adolescents, hence hesitate to allow much independence.

Research shows that social support from family and peers enables the adolescents to cope with and accept their epilepsy, with special mention of parental support (Chew et al., 2017; Chong et al., 2016). Furthermore, it is reported that those who experience epilepsy as most debilitating are not those who experience severe seizures, but rather those who lack a good social support system (Mameniškienė et al., 2017). The current study found that parental support is vital to certain individuals and that these limitations to social freedom also exist – with the intention of keeping the individual safe. Family members limit social outings such as sleepovers, participating in unsupervised activities, and are more vigilant. This is also reflected in the literature, which states that such relationships with family can be challenging when it comes to restrictions on social activities, loss of autonomy and limited independence (Chew et al., 2017). While some of the findings of the current study reiterated difficult social relationships with peers due to stigma and feeling “different” from others, some findings also revealed that peers can play a role in providing support and a sense of acceptance. This difference in feelings towards the role of peers in the life of an adolescent with epilepsy is parallel to the existing research (Chew et al., 2017).

6.2.3.4 Attitudes and outlooks on living with epilepsy

The findings of the current study showed that though epilepsy is still a stigmatised disorder in many cases, some participants did not dwell on the “label” of epilepsy, but rather were vocal to those around them about having epilepsy, so that they would be aware should the person experience a seizure. This is consistent with literature and according to a study conducted by Sheridan et al. (2016) young persons with epilepsy disclose that they have epilepsy in order to secure allies who would respond appropriately should they experience a seizure. The participants in this study, however, still spoke about not wanting to be different from others, and this may prevent them from disclosing their diagnosis of epilepsy to others.

6.2.4 Theme 4: Emotional insights

Through this study, participants were encouraged to express their own view of the world they live in and more importantly, how they feel about and experience this world, and to be introspective without enforced limitations or guidelines. A reflection of the person’s subjective truth is the crux of what this study encompasses, and it was found that the participants were expressive about their own feelings and emotions.

6.2.4.1 Self-awareness and reflections

The social relational model of disability of Thomas (2004) speaks about how chronic illnesses have an influence on social participation – they result in barriers of doing and barriers of being. Barriers of doing relate to activities that an individual cannot partake in due to their tiredness, fatigue, or any other symptom of their illness, while barriers of being refer to unfulfilled potential and the negative responses that these individuals get from others, which may poorly influence their psycho-emotional health (Chew et al., 2019).

In a study by Pauschek et al. (2016), it was reported that most children could express how they felt when they experienced a seizure, both physically and also talking about the emotional aftermath or preceding feelings. The current study found that participants could articulate feelings related to the experience of a seizure. Some reported not having any memory of the seizure itself, but were able to give context either before or after the occurrence of the seizure, as well as an account from others who were with them when they experienced a seizure.

6.2.4.2 Aspirations

Research showed that children and adolescents with epilepsy may exhibit anxieties about not accomplishing or reaching certain goals due to their epilepsy (Chong et al., 2016; Wo et al., 2018). Although some fear was expressed by participants in this regard in the current study, the overall attitude towards achieving goals was found to be one of optimism and unwavering motivation. Participants in this study expressed their aspirations and expressed having no doubt that they would achieve their goals. In fact, no direct mention of epilepsy was made when the participants talked about achieving their goals.

Reflective Diary: Insert 3

I was in awe of how insightful and aware these adolescents were of themselves and how open they were to discuss their insecurities, vulnerabilities, and challenges. They displayed a level of emotional maturity and a longing to be heard.

6.2.5 Summary of findings

The findings of the current study together with correlating or conflicting literature are presented side by side to give insight into the experiences of three adolescents living with epilepsy in South Africa and the uniqueness of each experience in terms of personal factors, family or institutional context, comorbidities, and personal beliefs is also highlighted. Furthermore, the discussion of these findings lends insight and contributes an understanding of the lived experiences of these adolescents. The findings of the current study indicated that the participants experienced cognitive challenges such as memory problems which impaired their daily functioning and had an influence on academic performance. The participants also experienced psychological challenges, specifically anxiety, depression, and fears specifically related to their epilepsy. The participants described an array of experiences with medical treatment, unique social challenges, family dynamics, and support systems related to their epilepsy. These lived experiences in turn influenced the emotions, insights, and ambitions of the participants, some of which they reflected upon. In the next section, the limitations of the study are acknowledged and discussed.

6.3 Limitations of the study

The researcher accepts that truth is subjective and that that in line with IPA the interpretations are influenced and created through the researcher's own experiences and beliefs. Therefore, it is fair to say that the interpretations have been co-constructed by the participants and the researcher. IPA advocates that the researcher should acknowledge and explore his/her role. The researcher should be explicit about their thoughts and feelings as these are valuable components of inquiry (as demonstrated in the section titled "Personal reflections" further on in this chapter as well as in the diary inserts found throughout this chapter). Furthermore, the co-construction of data between researcher and participant is considered a legitimate and valuable component of the research (Biggerstaff & Thompson, 2008).

The next limitation is the lack of variation in terms of gender. All three of the participants were female, leaving the male view unrevealed. This was, however, not done intentionally, but rather because the recruitment process was conducted objectively by a third party (Epilepsy SA) and as such the researcher did not have any control over participant selection.

The researcher was able to recruit only three participants due to difficulties in the recruitment process as discussed in section 6.4. The content of some of the interviews conducted is also limited given the cognitive and developmental factors of the participants. These challenges may have reduced the possible quantity of data that could have been collected. The researcher did deem some degree of data saturation to be reached due to the same themes emerging through the analysis of the interview transcripts, however, it is accepted that further interviews may have likely yielded new themes and more in-depth data.

Owing to the neurodevelopmental nature of a condition like epilepsy, participants were diagnosed and treated for different lengths of time and at different ages. This may have shaped how they experienced living with epilepsy and hence may have informed the findings obtained.

Only one interview was conducted with each participant, and this may have limited the depth of the information that was acquired. This was done in the pursuit of convenience for the participants, limited time and resources (data usage for online platforms).

All participants were able to converse in basic English. Conducting the interviews in English may be a limitation if it was not the mother tongue of the participant. This could have reduced the richness and depth of the details of the lived experiences narrated and some meaning may have been lost.

The interviews were conducted via Zoom (due to Covid restrictions) and this sometimes resulted in poor network connectivity and poor audio on both ends. These interruptions may have had an impact on the depth of the interview and the consistent contact which contributes to rapport.

6.4 Recommendations for future research

As indicated earlier in this chapter, previous research suggested that the experiences of young people with epilepsy are likely to differ in different cultures. South Africa is a country rich in cultural variety and this necessitates more studies to be undertaken that focus on the experiences of individuals from different cultural contexts and comparing these experiences. This would also enable a more nuanced understanding of the experiences of young people with epilepsy.

Furthermore, future studies could include larger, more diverse samples so that a broader and more inclusive view of different people (varied in gender, background, culture, and beliefs) may be explored, better understood, and generalised to the larger population – the diverse population of South Africa’s youth with epilepsy.

6.5 Personal reflections

I, as the researcher, have attempted above all to be reflexive in every aspect of this study process, from planning, to conducting interviews, to data analysis and finally interpreting the findings. Upon beginning the process, I was motivated and in high spirits as the topic of epilepsy has a significant meaning in my life. I have my own lived experiences as a witness to someone living with epilepsy. I have witnesses how debilitating the experience of a seizure can be, especially due to the unpredictable nature of these seizures. I have also witnessed the public’s reaction to seizures being one of fear or discomfort. The stigmatisation associated with epilepsy that is still very much a part of the society we live in; we do not talk about the disorder, and in return others pretend as if it does not exist. This perhaps is the first reflection I, the researcher, need to make. This topic, though personal, felt academically important and I knew I could do it justice because the cause was important. There were many challenges along the way; unanticipated, to say the least.

My most challenging process proved to be the recruitment process. Epilepsy SA was wonderfully accommodating and provided me access to their database through a social worker. The catch was, though, that my sample age and their database did not quite link up. Members aged 13-19 were limited. The other consideration was that most of this age group (those under 18) required parent/guardian consent and many parents were apprehensive about allowing their children to speak about their epilepsy. This, I feel, attests to the still misunderstood nature of the disorder. Another contributing factor that caused delays was the backdrop of the Covid-19 pandemic and its unique set of restrictions. My first interview came about with ease, but thereafter I experienced a long wait for the next. It turned out to be a year-long pursuit filled with many rejections. Certain people agreed to participate, but failed to follow up with me about available dates and times, and eventually cancelled. I had an experience with one potential participant’s parent who had misunderstood the study invitation or perhaps her communication with the social workers was unclear and she approached me hoping to gain some monetary help for her child’s condition. I clarified the aim of the study and moved forward. I was finally put in contact with another participant, followed by another two months of waiting. My final participant was interviewed just before the year ended, days before my wedding.

This back-and-forth process was perhaps the most stressful and exhausting, to the point of leaving me believing the study could not be achieved. It was at this point that I relied on the supervision and guidance of my supervisors to persevere. I went back to the foundation of IPA which focuses more on quality than quantity of participants, encouraging me to fully commit to the interviews I did manage to successfully conduct. During the transcription stage I started focusing on non-verbal cues and realising the significance of context.

Reflective Diary: Insert 4

It has been months without recruiting a new participant. I find myself frustrated and anxious about whether I will receive news of another participant. I need to be aware that the energy I brought to the first interview may not be the energy I bring to this next one. But it's important I remember my role and give every participant the same respect and empathy to tell their story.

In the beginning of my interviews, I held the assumption that epilepsy was a highly stigmatised and misunderstood condition in most, if not all, communities and that those with epilepsy viewed it as a label – a label of being crazy, possessed, infectious or cursed. This was not entirely true and as I conducted my interviews, I realised that different people viewed their epilepsy differently and that the reactions to having epilepsy were actually neutral and accepting in some contexts. Another assumption that I held, was that I would find participants who would do all the talking and I would simply have to probe and acquire deeper information. Though this assumption proved to be true in the initial interviews, I soon realised that this was not easy subject matter. Not every participant was keen on opening up regarding all aspects and it was also true that not everyone had the words to express the deepest parts of themselves. I also discovered, however, that a lot was said non-verbally. The experience with my last participant was one I did not expect; I was rattled and unsure and I sought supervision. My supervisors reminded me that not communicating is also communicating and that really changed my perspective.

Reflective Diary: Insert 5

I've struggled to get responses from potential participants – One mother was keen to facilitate the interview at first but later refused. It leaves me reflecting on what it must be like for them – to be totally open and vulnerable and allow your child to speak about something quite sensitive – perhaps the epilepsy is something they still struggle with and feel uncomfortable sharing right now.

I am a novice researcher in general and specifically within the paradigm of IPA, and I felt the need to constantly go back and consult the literature and guidelines of the methodology, especially with regard to the data analysis. I also needed to find a balance between keeping in mind the aim of the study and allowing participants the freedom and flexibility to speak in the interviews. I found myself feeling deeply empathetic toward my participants and had to remind myself to exercise caution and not to snap into saviour mode, but rather to channel that empathy into listening and being genuine throughout. Owing to my experiences, I am aware that I view epilepsy through a lens of empathy and as a topic that is not publicly discussed, and this would come through in my analysis and interpretation of the data. Furthermore, I believe in the importance of independence, education, and family- these values may have also influenced my interpretations of the data. I believe the uneasiness I once felt discussing epilepsy openly has evolved through my research. As much as I have influenced my findings, this process has bidirectionally influenced me. Today I can more confidently address my opinions, even in the face of stigma.

I was deeply moved by the stories the participants shared with me. I was so grateful for their courage to open up and speak to a stranger. Their challenges stirred me, but I think what touched me most was the spark with which they spoke about their dreams for the future; that motivation and drive to want something so much and to be certain you will achieve it. It is their insights and reflections that came out randomly and towards the end of the interview, that stay with me and will stay with me. I was able to interact with these young persons who were so honest about who they are, who reflected on themselves and the world around them so critically, who have been through trials and continue to see challenges, and who reminded me how every subjective truth is factual and real, and for that I will be always grateful.

6.6 Conclusion

This concluding chapter provided the researcher's interpretation of the themes identified as well as insight and reflection on the significant aspects of the study conducted together with existing literature on the topic. It was also explained how past research complements or contrasts what was found in the current study. The chapter concluded with personal reflections of the researcher on the research process, the data collection, possible biases, and overall outlook. The findings of this study reiterated the complexities and unique challenges that living with epilepsy poses for the adolescent in this transitional phase of life. Furthermore, the findings emphasised the importance of mental healthcare for these individuals and highlighted the need for more studies to fully understand the specific needs these adolescents have as well as the need for interventions.

The experience of epilepsy is social, emotional, psychological, cognitive, as well as physical and this fact is so fundamentally overlooked.

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Appendix A: Informed Consent

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019
Department of Psychology

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH – PARENTS

Researcher's Details:

Zahrah Moosa
zahrahmoosa.moosa7@gmail.com or 072 418 1381

TITLE OF THE STUDY
Experiences of adolescents living with epilepsy in South Africa

Dear parent or guardian of the participant,

My name is Zahrah Moosa and I am currently a master's student in the Department of Psychology at the Faculty of Humanities, University of Pretoria.

PURPOSE OF THE STUDY

The purpose of this study is to obtain an understanding of the experiences of adolescents living with epilepsy in South Africa. Very few studies have been conducted from the perspective of the individual with epilepsy, and even fewer studies have been conducted from the perspective of the adolescent with epilepsy. I have decided to conduct a study on the lived experiences of these individuals. The overall aim of this study is to gain insight into and a better understanding of the experiences of living with epilepsy from an adolescent's perspective.

PROCEDURE

Your adolescent child (age 13 - 19) diagnosed with epilepsy will be invited to participate in the research. Participation in this research study involves an interview session between me, the researcher, and your adolescent child. This interview will either be conducted face-to-face or via video call. During this interview, I would like to ask your child about the general experience living with epilepsy and the impact of this disorder on his/her life. The duration of the interview will be approximately 60-90 minutes long. This interview session will be recorded.

POTENTIAL BENEFITS

The direct benefits for the participant would be an opportunity for the participant to share his/her experiences. However, I cannot compensate for yours and your child's time and energy for which I am profoundly grateful. My

RISKS OR DISCOMFORTS

No physical or emotional risks are foreseen at this point however, given that the subject matter is sensitive and personal, some participants may experience distress when talking about these issues. Should the participant feel distressed at any point during the interview, the interview will be terminated and only continued if and when the participant choses. Measures to minimize these risks will include a debriefing session after the interview, in which the participant may ask any questions that he/she may have regarding the study. Should the participant feel distressed and require further assistance, I will refer him/her free of charge, to clinical psychologist, Namrata Ranchhod (PR. No. 8639302). The contact email address is namrata.ranchhod@gmail.com.

PARTICIPANTS' RIGHTS

Participating in this study is voluntary and the participant can withdraw from participating in the study at any time without any negative consequences. All data and records will be destroyed should the participant decide to withdraw.

CONFIDENTIALITY

I will make sure to remove all identifying features including the participant's name and replace this with pseudo names or fake names to ensure that confidentiality is maintained.

RIGHT OF ACCESS TO RESEARCHER

Should you require any information or clarity, you can contact me at any time during the research process.
(Details provided on the form).

FURTHER RESEARCH

Electronic information will be stored for a minimum period of 15 years by the Department of Psychology. You hereby also give consent that data can be used for further research, future articles, conferences, teaching, etc, as required.

I, (name and surname of parent/guardian) ____ hereby give permission for (name and surname 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 B: Informed Assent

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019
Department of Psychology

INFORMED ASSENT
FOR PARTICIPATION IN RESEARCH

Researcher's Details:

Zahrah Moosa
zahrahmoosa.moosa7@gmail.com or 072 418 1381

TITLE OF THE STUDY

Experiences of adolescents living with epilepsy in South Africa

Dear participant,

My name is Zahrah Moosa and I am currently a master's student in the Department of Psychology at the Faculty of Humanities, University of Pretoria.

PURPOSE OF THE STUDY

The purpose of this study is to obtain an understanding of the experiences of adolescents living with epilepsy in South Africa. Very few studies have been conducted from the perspective of the individual with epilepsy, and even fewer studies have been conducted from the perspective of the adolescent with epilepsy. I have decided to conduct a study on the lived experiences of these individuals. The overall aim of this study is to gain insight into and a better understanding of the experiences of living with epilepsy from an adolescent's perspective.

PROCEDURE

Participation in this study involves a once-off interview session with me. The interview will either be conducted face-to-face or via videocall. During this interview I would like to ask you about the general experience of living with epilepsy and the impact of this disorder on the different spheres of your life- personal, academic, family life etc. The interview will be approximately 60-90 minutes long. This interview session will be recorded. I will provide enough time after the interview should you have any follow-up questions.

POTENTIAL BENEFITS

The direct benefits would be an opportunity to tell your story and share your experiences. However, I cannot compensate for your time and energy for which I am profoundly grateful. My hope is that the information obtained

RISKS OR DISCOMFORTS

No physical or emotional risks are foreseen at this point in time however, given that the subject matter is sensitive and personal in nature, some participants may experience distress when talking about these issues. Should you feel distressed at any point during the interview, the interview will be terminated and only continued if and when you decide so. Measures to minimize these risks will include a debriefing session after the interview, in which the participant may ask any questions that he/she may have regarding the study. Should you feel distressed and require further assistance I will refer you, free of charge, to clinical psychologist, Namrata Ranchhod (PR. No. 8639302). The contact email address is namrata.ranchhod@gmail.com.

PARTICIPANTS' RIGHTS

Participating in this study is voluntary and you can withdraw from participating in the study at any time without any negative consequences. All data and records will be destroyed should you decide to withdraw.

CONFIDENTIALITY

I will make sure to remove all identifying features including your name and replace this with pseudo names or fake names to ensure that your identity remains hidden and confidentiality is maintained.

RIGHT OF ACCESS TO RESEARCHER

Should you require any information or clarity, you can contact me at any time during the research process.
(Details provided on the form).

FURTHER RESEARCH

Electronic information will be stored for a minimum period of 15 years by the Department of Psychology. You hereby also give consent that data can be used for further research, future articles, conferences, teachings, etc, as required.

1. I, (name and surname of participant) ____ hereby give permission to participate in the research. I have received sufficient information and I have had the opportunity to discuss any uncertainty.

   Child (signature) ___________________________

   Signed at (place) ____________________________on (date)___________________________

2. I, (name and surname of parent/guardian) ____ hereby give permission for (name and surname 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 C: Written Consent

UNIVERSITEIT VAN PRETORIA
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YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019
Department of Psychology

Experiences of Adolescents living with Epilepsy in South Africa

{ETHICAL APPROVAL NUMBER} (If available**)**

WRITTEN CONSENT TO PARTICIPATE IN THIS STUDY

I, _________________________ (**Parent/Guardian name**), confirm that the person asking my consent to take part in this research has told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

STATEMENT	AGREE	DISAGREE	NOT APPLICABLE
I understand that my child's participation is voluntary and that he/she is free to withdraw at any time, without giving any reason, and without any consequences or penalties.			
I understand that information collected during the study will not be linked to my child's identity and I give permission to the researchers of this study to access the information.			
I understand that this study has been reviewed by, and received ethics clearance from Research Ethics Committee Faculty of Humanities of the University of Pretoria.			
I understand who will have access to personal information and how the information will be stored with a clear understanding that, I will not be linked to the information in any way.			
I give consent that data gathered may be used for dissertation, article publication, conference presentations and writing policy briefs.			
I understand how to raise a concern or make a complaint.			
I consent to my child being audio recorded.			
I consent to my child being video recorded.			
I consent to having my child's photo taken.			
I consent to have the audio recordings /videos/photos be used in research outputs such as publication of articles, thesis and conferences as long as my identity is protected.			
I give permission for my child to be quoted directly in the research publication whilst remaining anonymous.			

Name of Parent/Guardian	Date	Signature
Name of person taking consent	Date	Signature

Appendix D: Written Assent

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019
Department of Psychology

Experiences of Adolescents living with Epilepsy in South Africa

{ETHICAL APPROVAL NUMBER} (If available**)**

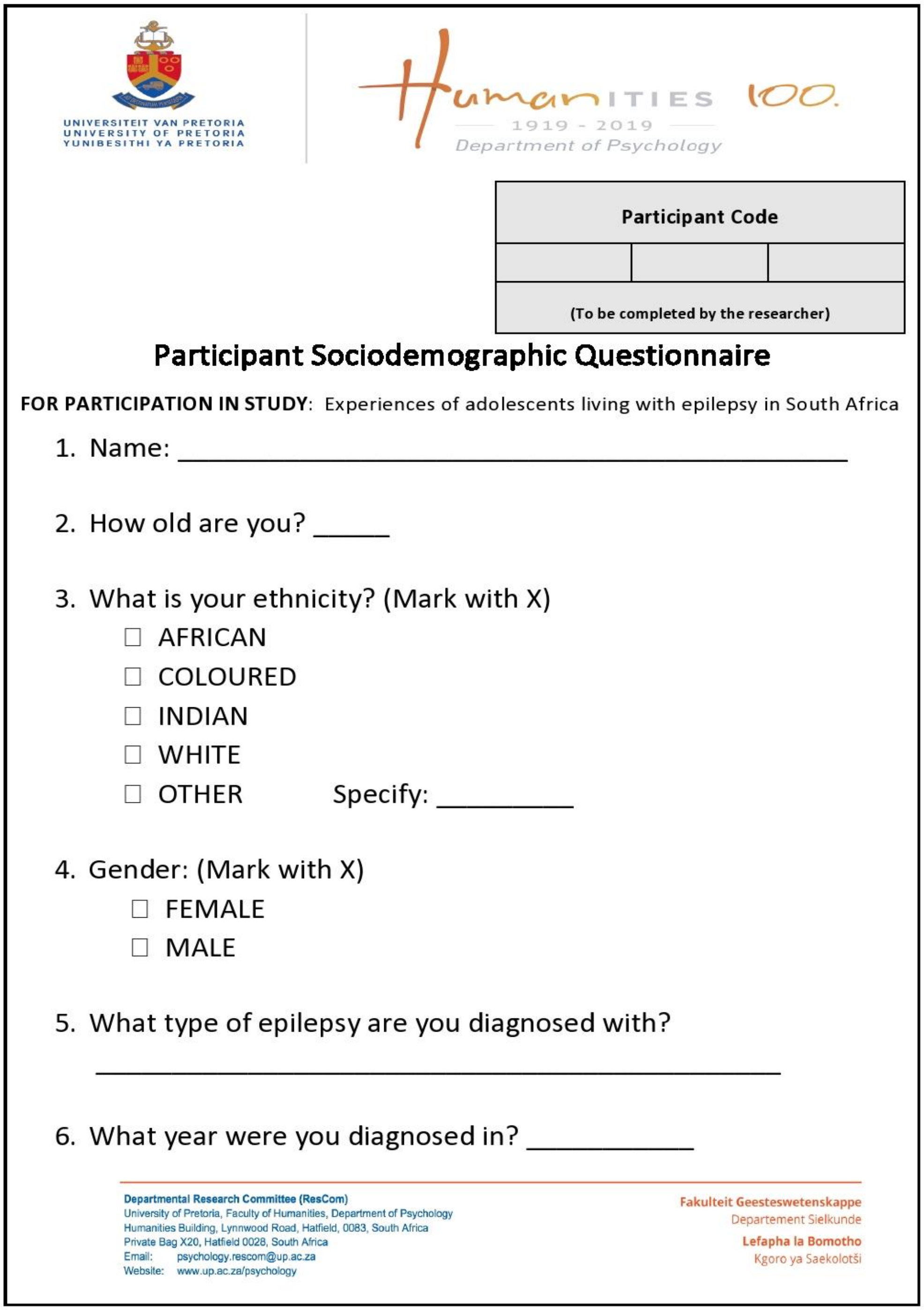
WRITTEN ASSENT TO PARTICIPATE IN THIS STUDY

I, _________________________ (**participant name**), confirm that the person asking my consent to take part in this research has told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

STATEMENT	AGREE	DISAGREE	NOT APPLICABLE
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any consequences or penalties.			
I understand that information collected during the study will not be linked to my identity and I give permission to the researchers of this study to access the information.			
I understand that this study has been reviewed by, and received ethics clearance from Research Ethics Committee Faculty of Humanities of the University of Pretoria.			
I understand who will have access to personal information and how the information will be stored with a clear understanding that, I will not be linked to the information in any way.			
I give consent that data gathered may be used for dissertation, article publication, conference presentations and writing policy briefs.			
I understand how to raise a concern or make a complaint.			
I consent to being audio recorded.			
I consent to being video recorded.			
I consent to having my photo taken.			
I consent to have my audio recordings /videos/photos be used in research outputs such as publication of articles, thesis and conferences as long as my identity is protected.			
I give permission to be quoted directly in the research publication whilst remaining anonymous.			

____________________________	______________	_______________
Name of Participant	Date	Signature
____________________________	______________	_______________
Name of Parent/Guardian	Date	Signature
____________________________	______________	______________
Name of person taking consent	Date	Signature

Appendix E: Interview Guide and Sociodemographic Questionnaire



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Participant Code		
(To be completed by the researcher)		

Participant Sociodemographic Questionnaire

FOR PARTICIPATION IN STUDY: Experiences of adolescents living with epilepsy in South Africa

1. Name: ____

2. How old are you? _____

3. What is your ethnicity? (Mark with X)
   - ☐ AFRICAN
   - ☐ COLOURED
   - ☐ INDIAN
   - ☐ WHITE
   - ☐ OTHER Specify: _________

4. Gender: (Mark with X)
   - ☐ FEMALE
   - ☐ MALE

5. What type of epilepsy are you diagnosed with?

   ____

6. What year were you diagnosed in? ___________

Departmental Research Committee (ResCom)
University of Pretoria, Faculty of Humanities, Department of Psychology
Humanities Building, Lynnwood Road, Hatfield, 0083, South Africa
Private Bag X20, Hatfield 0028, South Africa
Email: psychology.rescom@up.ac.za
Website: www.up.ac.za/psychology

Fakulteit Geesteswetenskappe
Departement Sielkunde
Lefapha la Bomotho
Kgoro ya Saekolotši

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YUNIBESITHI YA PRETORIA

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1919 - 2019
Department of Psychology

Interview Guide

At the onset of the interview, participants will be put at ease as the researcher builds a rapport or trust relationship with the participant

The participant will be asked to complete a demographic questionnaire asking for their name, age, gender, ethnicity, type of epilepsy, and duration of diagnosis.

The participant will be briefed on what is expected from them during this interview i.e. – to discuss their experience of living with epilepsy.

The researcher will commence the interview by thanking the participant for consenting to participate in the study. Consent to record the session on a tape recorder or electronic recording of an online interview session will also be confirmed at this point.

An initial open -ended question will be asked in relation to their experience living with epilepsy and follow up questions or prompts will be asked thereafter.

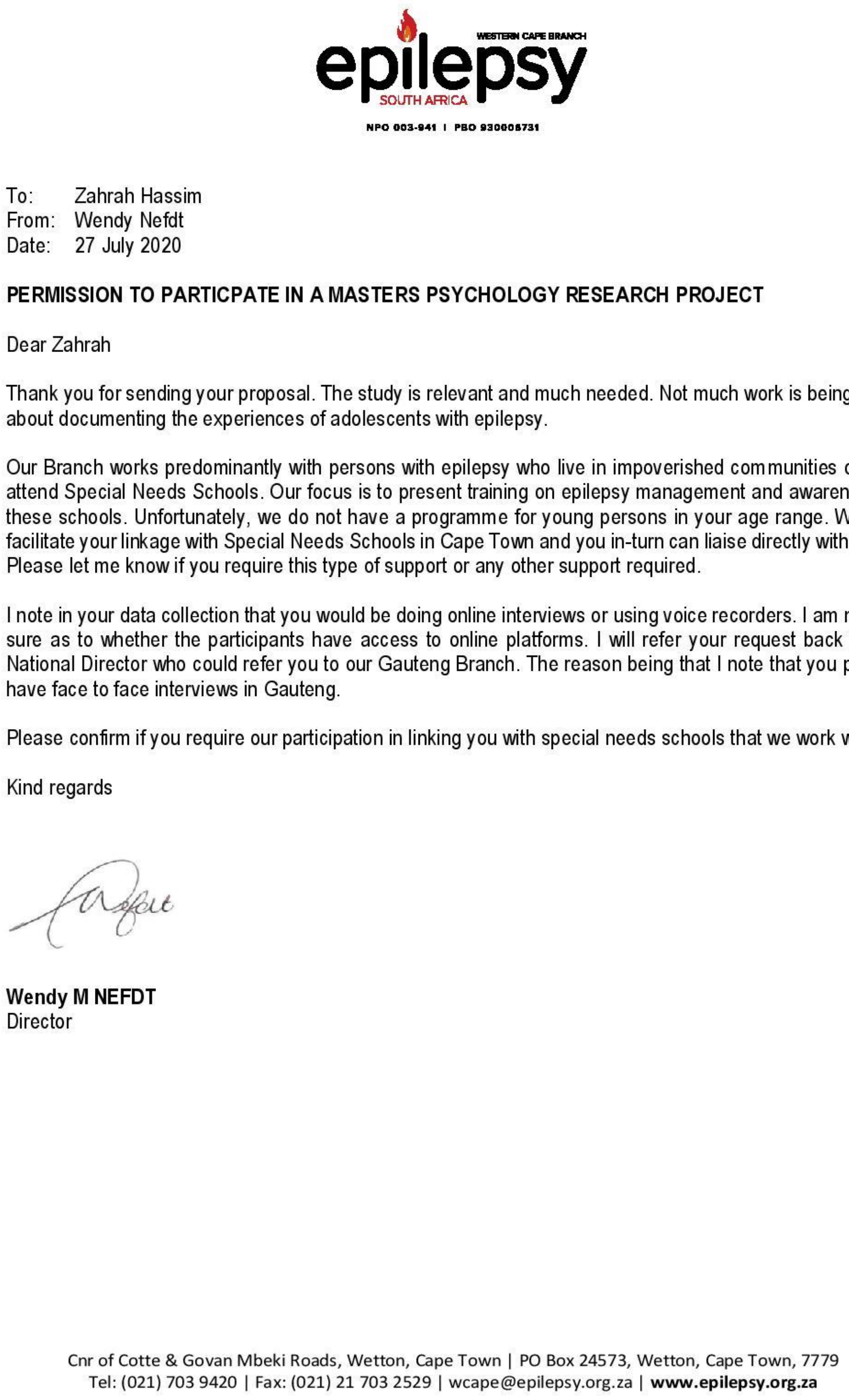
Possible open- ended questions and prompts:

- Describe your experience with epilepsy.
- What is it like living with epilepsy? Describe a day in your life.
- How has life changed since your diagnosis?
- How do you feel about these changes?
- What impact has living with epilepsy had on your life?
    - How has it impacted family life?
    - How has it impacted your relationships?
    - How has it impacted your academic life?
- What advice would you give someone who is living with epilepsy?
- Is there anything else you would like to talk about or add?

Prompts

How do you feel about that? Can you give me an example?
Could you elaborate?

Appendix F: Letter from Epilepsy SA



WESTERN CAPE BRANCH
epilepsy
SOUTH AFRICA
NPO 003-941 | PBO 930008731

To: Zahrah Hassim
From: Wendy Nefdt
Date: 27 July 2020

PERMISSION TO PARTICPATE IN A MASTERS PSYCHOLOGY RESEARCH PROJECT

Dear Zahrah

Thank you for sending your proposal. The study is relevant and much needed. Not much work is being done about documenting the experiences of adolescents with epilepsy.

Our Branch works predominantly with persons with epilepsy who live in impoverished communities or who attend Special Needs Schools. Our focus is to present training on epilepsy management and awareness in these schools. Unfortunately, we do not have a programme for young persons in your age range. We can facilitate your linkage with Special Needs Schools in Cape Town and you in-turn can liaise directly with them. Please let me know if you require this type of support or any other support required.

I note in your data collection that you would be doing online interviews or using voice recorders. I am not too sure as to whether the participants have access to online platforms. I will refer your request back to our National Director who could refer you to our Gauteng Branch. The reason being that I note that you plan to have face to face interviews in Gauteng.

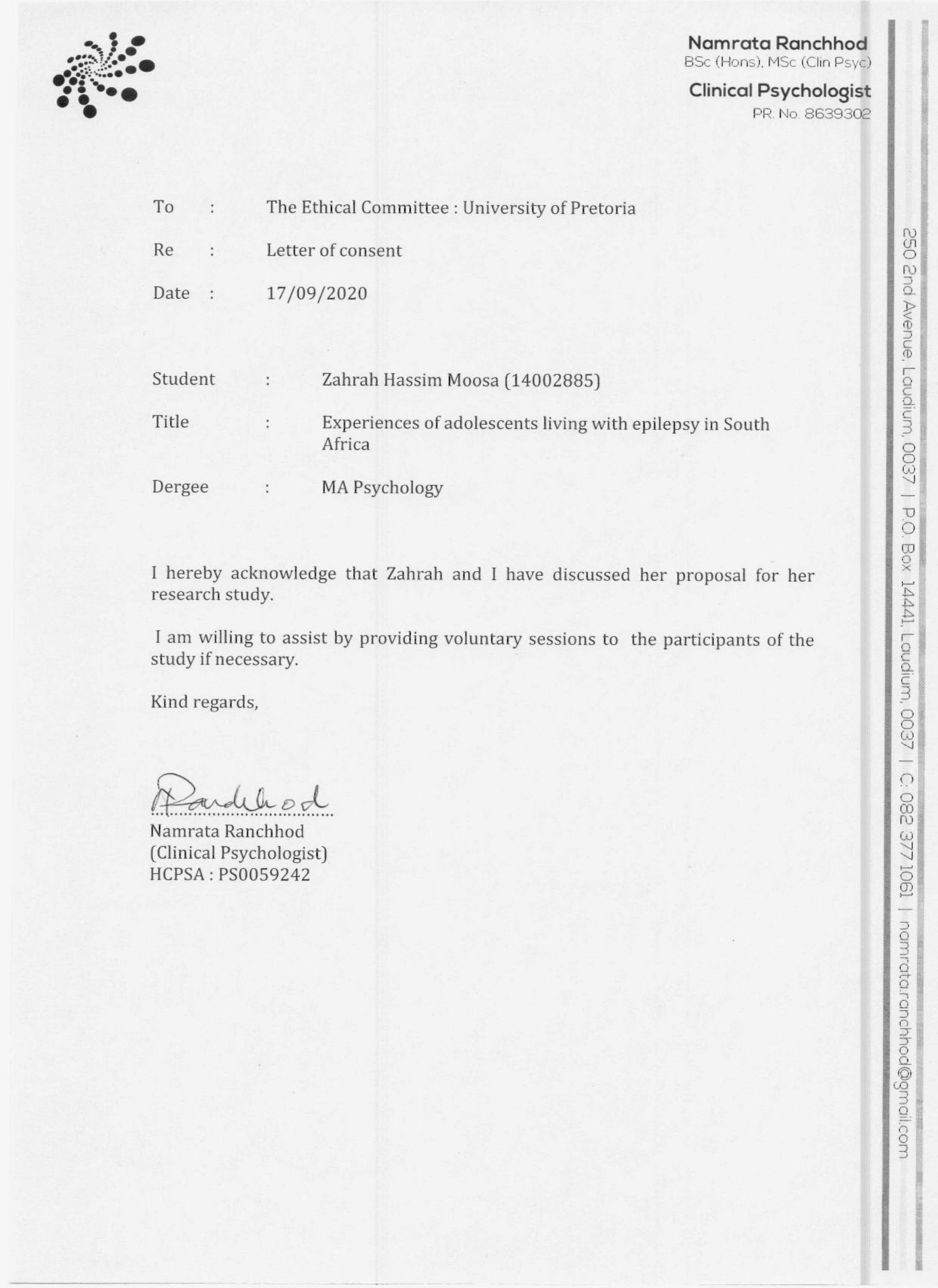
Please confirm if you require our participation in linking you with special needs schools that we work with.

Kind regards

Wendy M NEFDT
Director

Cnr of Cotte & Govan Mbeki Roads, Wetton, Cape Town | PO Box 24573, Wetton, Cape Town, 7779
Tel: (021) 703 9420 | Fax: (021) 21 703 2529 | wcape@epilepsy.org.za | **www.epilepsy.org.za**

Appendix G: Consent letter from psychologist



Namrata Ranchhod
BSc (Hons), MSc (Clin Psyc)
Clinical Psychologist
PR. No. 8639302

To : The Ethical Committee : University of Pretoria
Re : Letter of consent
Date : 17/09/2020

Student : Zahrah Hassim Moosa (14002885)
Title : Experiences of adolescents living with epilepsy in South Africa
Dergee : MA Psychology

I hereby acknowledge that Zahrah and I have discussed her proposal for her research study.

I am willing to assist by providing voluntary sessions to the participants of the study if necessary.

Kind regards,

Ranchhod
Namrata Ranchhod
(Clinical Psychologist)
HCPSA : PS0059242

250 2nd Avenue, Laudium, 0037 | P.O. Box 14441, Laudium, 0037 | C: 082 377 1061 | namrata.ranchhod@gmail.com