Examining the contribution of Epilepsy Specialist Nurses (ESNs) to paediatric epilepsy services from the carer perspective.

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Declaration

I declare the work presented in this thesis is, to the best of my knowledge, original and my own work. The material has not been submitted, in part or whole, for any other higher degree at this, or any other University. This thesis does not exceed the maximum permitted word length of 80,000 words.

Rebekah Elizabeth Beesley

Abstract

The purpose of this research was to compare paediatric epilepsy services with and without Epilepsy Specialist Nurse (ESN) provision from the carer perspective. Two studies were conducted as part of a mixed-methods design; a questionnaire study in which measures of carers satisfaction, need and accessibility were investigated and an interview study where perspectives from carers concerning their relationships with paediatric epilepsy services were analysed.

In the questionnaire study, carers in Northern England (n = 69 with an ESN, n = 27 without an ESN), completed the Parent Report of Psychosocial Care Scale to measure satisfaction with service provision. A measure of accessibility of service was also included. Satisfaction with service levels were high across all areas, (ESN areas *Mdn* = 9.04, *IQR* = 1.48, non-ESN areas *Mdn* = 8.29, *IQR* = 2.41; maximum score = 10), but with carers from ESN areas over 3 times more likely to endorse scores at the median or above relative to non-ESN areas (*OR* = 3.28). For accessibility, carers in ESN areas were over 5 times more likely to have a median score or higher (ESN areas *Mdn* = 10, *IQR* = 0.45, non- ESN areas *Mdn* = 8.4, *IQR* = 5, *OR* = 5.43).

In the interview study, semi-structured interviews with 58 carers (51 had completed the questionnaire), 37 from service areas with an ESN, and 21 from areas without an ESN in the North-West of England, were conducted and analysed using Thematic Analysis adopting a realist epistemological position. Four themes relating to different aspects of carers' needs were identified. These were needs for *understanding the condition, condition management support, educational liaison support*, and *emotional support*. The ESNs were able to meet these diverse support needs of families proactively and sensitively, whereas in services without ESNs, carers were left to attempt to fulfil needs across different contexts in an ad hoc manner.

In conclusion, paediatric ESNs provide a critical and timely service to children with epilepsy and their carers. ESNs are an essential resource for all involved in the care of CWE and they help to mitigate carer burden. Further, the findings highlight the need for improved outcome measures that assess timeliness and optimal carer solutions in communications with services between regular appointments in order to adequately and effectively capture outcomes of ESN provision and the variety of problems they solve.

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Chapter One: Paediatric Epilepsy

1.1 Introduction

Epilepsy is one of the most common neurological disorders in childhood (Rodenburg et al., 2005). It is a serious condition that is characterised by unpredictable seizures. Seizures are triggered by a sudden surge of electrical activity in the brain and occur due to complex chemical changes within the nerve cells in an epileptiform region. This seizure activity can occur in any of the regions of the brain and can therefore affect a range of functional systems. The location of onset and subsequent areas of the brain involved, the speed at which seizure activity spreads and the length of an episode can all affect the way in which a seizure is experienced by an individual. Currently there are at least 40 different types of recognised seizures, 29 known epilepsy syndromes and 12 clinically distinct groups that can be defined by an underlying cause (Joint Epilepsy Council [JEC], 2011). In order to classify seizure types they are first defined by onset. Seizures are categorised on a basic level as focal, generalised or of unknown onset (Fisher et al., 2017). Focal seizures are limited to one hemisphere and may be localised or more widespread whereas generalised seizures involve activation in both hemispheres. Further classification of seizures can be made for specific features such as motor onset, non-motor elements and in focal seizures whether the patient has awareness or impairment of awareness (Falco-Walter et al., 2018). Seizure types are distinct classifications and are not to be confused with epilepsy type. People can experience multiple seizure types but epilepsy type requires separate categorisation. The current International League Against Epilepsy (ILAE) classifications published in 2017 explain that epilepsies are now divided into four categories; focal, generalised, combined generalised and focal and unknown (Fisher et al., 2017). Again this is a separate categorisation to epilepsy syndromes which refer to clusters of features

including seizure type(s), triggers, test results and age-dependent features that occur together. However, not all seizures are due to epilepsy. Epileptic seizures are due to the spontaneous tendency for epileptiform discharges to occur whereas other medical issues can cause seizure activity e.g. a high temperature can result in febrile seizures (Berg et al., 1995). It is reported that up to 10% of the population experience a seizure during the course of their life (World Health Organisation [WHO], 2009). With this level of seizure activity in the general population, it is imperative that a diagnosis of epilepsy is made by a specialist clinician with expert knowledge and experience. There are no conclusive tests for epilepsy so a range of information is gathered to make a diagnosis. This can include, but is not limited to, witness accounts and video evidence of the seizures, detailed patient history, genetic testing and results of Electroencephalography (EEG) and Magnetic Resonance Imaging (MRI). In some cases, it can take considerable time for a diagnosis to be made as seizure activity cannot always be captured at the time of testing.

The prevalence rate in the UK for patients under the age of 16 is approximately 51,500 or 1 in 240 with the incidence rate for new onset cases in children and adolescents approximately 4.8 per 10,000 (JEC, 2011). However, more recent studies have determined epilepsies in early childhood to be up to 30% more common than previously reported (Symonds et al., 2021). Epilepsy can occur at any age. In some cases, an underlying cause can be identified such as lesions, infection or brain damage from problematic birth and is classified as symptomatic or probable-symptomatic epilepsy. However, for at least 60% of children the epilepsy is idiopathic where the cause is unknown (JEC, 2011). Clinicians are encouraged to consider epilepsy aetiology from initial contact and the ILAE guidance (2017) is that there are six categories; structural, genetic, infectious, metabolic, immune and unknown. These categories are

not hierarchical and in some cases more than one may apply (Scheffer et al., 2017). In recent years there has been a shift in categorisation to Genetic Generalised Epilepsies (GGEs) and Developmental and Epileptic Encephalopathies (DEEs) (Hirsch et al., 2022). GGEs are mainly genetically determined disorders with complex inheritance (Mullen et al., 2018). Idiopathic generalized epilepsies (IGEs) are a subgroup of GGEs, comprised of four syndromes: childhood absence epilepsy, juvenile absence epilepsy, juvenile myoclonic epilepsy, and epilepsy with generalized tonic–clonic seizures (Gauer et al., 2024). DEEs are the most severe group of epilepsies categorised by drug resistant seizures and developmental regression (Scheffer et al., 2025).

Once a diagnosis has been made there are various treatment options available. The most common is medical management in the form of anti-epileptic drugs (AEDs). There are a variety available and an experienced consultant would be able to determine the most effective options in terms of drug type and dose. In some cases, it can take time to find an effective combination and while the medication is increased or changed the patient can still experience breakthrough seizures. Although AEDs can have a positive effect on seizure activity there are a range of side-effects associated with some of the drugs that can significantly impact the patient and their quality of life. When medical management is unsuccessful alternative treatments can be considered such as a ketogenic diet, deep brain stimulation, vagus nerve stimulation (VNS) and for suitable intractable cases, neurosurgery.

When epilepsy occurs in childhood it can have significant implications for development (Austin & Caplan, 2007; Ronen et al., 2003a). This can include behavioural and cognitive disorders (Jensen, 2011), psychological and psychiatric consequences (Rodenburg et al., 2005) and impact on social environment (Sillianpää & Cross, 2009). Some of these issues can be compounded by comorbidities associated

with the condition (Reilly, et al., 2014). There is also evidence of reduced quality of life in children with epilepsy (Tanriverdi et al., 2016; Cianchetti et al., 2015). A brief overview of each of the factors which impact children with epilepsy including a review of the associated literature will be presented in the following sections of this chapter.

1.2 Behavioural Difficulties

Children with epilepsy (CWE) are often reported as having higher rates of behavioural difficulties with some studies noting rates up to 5 times higher than in the general population and 2.5 times more than children with other non-neurological chronic conditions (Davies et al., 2003). There are consistent findings across a range of studies that highlight the heightened risk of CWE developing behaviour problems (Reilly et al., 2016; Dunn & Austin, 1999). A recent study by Reilly and colleagues (2019) found 76% of children diagnosed with epilepsy scored within the "at-risk" range of a strengths and difficulties questionnaire (SDQ) which is used to assess behavioural difficulties in preschool aged children. The researchers found CWE frequently had issues across a range of different behavioural domains. Studies of new-onset epilepsy have found these problem behaviours can occur in the early stages of the condition and even prior to the onset of seizures (Oostrom et al., 2003). Austin et al. (2001) conducted a study using parent-proxy behavioural measures and reported 32.1% of patients as having high rates of behaviour problems at clinical level in the first 6 months prior to any recognised seizure activity. They also reported that 39.5% of children with prior seizure activity met clinical threshold for at risk range behaviour. They noted significantly higher scores in children with seizures for internalising, attention, thought and somatic complaints when compared to nearest in age healthy siblings. These findings are consistent with a later 3 year follow up study which found significantly higher behavioural problem scores over time in CWE (11.3%) when compared to

healthy siblings (4.3%) (Austin et al., 2011). However, it should be noted that there has been evidence to suggest parent-proxy behaviour measures can be influenced by the emotional impact of the epilepsy on the parent and may warrant further interpretation (Eom et al., 2016). There is also evidence to suggest that in some cases parents are unaware that the behavioural problems exhibited by their children are linked to their epilepsy (Vona et al., 2009).

There are various factors that may contribute to behavioural problems in children. However, in children with epilepsy the risk of these factors having a significant effect is much higher. This may provide some explanation as to why the scores and risk factors are consistently higher when compared to children with other chronic conditions and healthy controls. Hermann & Whitman (1991) classify these factors into three categories; neurobiological, pharmacological and psychosocial. Neurobiological factors are associated with the neurological impact of epilepsy and include age of onset, seizure frequency, seizure severity, duration of illness and type of seizures. There have been various studies that suggest there is a positive correlation between behavioural problems and seizure severity and frequency (e.g. Austin et al., 2000; Austin et al., 1992). Austin and colleagues (2002) reported significantly higher rates of behaviour problems in children with older age of onset. They hypothesised this may be due to the increased awareness of seizures in older children and that older children would be more likely to worry about their condition than younger children, resulting in behavioural outbursts to cope with their feelings. Neuropsychological deficits are more prevalent in CWE and may be a risk factor associated with problem behaviour (Austin et al., 2011). Fastenau et al. (2009) reported lower rates of performance in children with epilepsy in all areas of neuropsychological functioning compared to healthy controls. Baum et al. (2010) suggest other impairments such as

language can also contribute to behaviour problems. Communication problems have also been linked to behavioural and attention difficulties within this population (Cohen et al., 1993). Caplan et al. (2004) also reported that CWE, particularly those with complex partial seizures (CPS), experienced more behavioural issues and exhibited poorer linguistic abilities. Schoenfeld et al. (1999) also reported epilepsy had a significant effect on behavioural measures in children with CPS.

Pharmacological factors include type and dose of anti-epilepsy medication (AED) prescribed. There are over 20 different types of AEDs (Epilepsy Society, 2019) and as with many other drugs there are risks of side-effects. The possible side-effects vary with each drug and their potential effect to the patient can also be quite differently. Two patients could be on the same dose and type of AED and yet the side effects experienced could be significantly different. Due to this variability it is very difficult to predict whether a patient will experience any side effects at all and if so, what type or severity. Therefore, it is important that patients are monitored when AEDs are prescribed or changed. The National Institute for Health and Care Excellence (NICE) have very specific guidelines for the treatment and management of epilepsy which medical professionals have to adhere to. This includes the individualisation of treatment strategies in line with the preferences of the patient and or parents/caregivers as deemed appropriate (NICE, 2012). If a parent or patient feels the side effects of a prescribed medication are negative and outweigh the clinical benefit they can request the medication be changed. The behavioural and cognitive impairment associated with AED treatment differ according to the specific drug prescribed (Loring et al., 2007; Lagae, 2006). Some of the most common AED behavioural side effects reported are increased aggression, mood changes, abnormal behaviours, irritability and agitation (Mula & Monaco, 2009). These behaviours can be difficult for parents to manage and

cause additional stress to the family. It should also be noted that most of the newer AED available are licenced for use in adults initially and the data for use in children can be limited in terms of cognitive and behavioural outcome measures (Moavero et al., 2017).

Psychosocial factors associated with behavioural problems include parental adaptation to illness, coping with stress, family dynamics including social and emotional support and socioeconomic issues. Issues with any of these factors are linked to increased risk of behavioural problems in CWE. Parenting a child with a chronic illness is a particularly challenging task due to the increased demands and constant adjustments that are required to meet the ever changing care needs of the child (Wallander & Varni, 1998). The level at which a parent is able to adapt to these changes and cope with needs can significantly impact the child. It is important that parenting behaviours are positive as they have a significant influence on the wellbeing and healthy development of the child. Although many parents are able to adapt positively to these challenges, a significant minority report issues with depression and condition management. In particular, poor maternal adaption is associated to high levels of internalizing behaviour problems in CWE (Shore et al., 2004).

Another important aspect of parenting a child with chronic illness is coping with the associated stress. Parenting stress is a risk factor for behaviour problems in CWE (Pianta & Lothman, 1994). Increased stress on the family unit can contribute to decreased adaptation outcomes (Garner et al., 2011). Studies such as Mims (1997) suggest in families where the child experiences higher frequency of seizures, the parents experience higher levels of stress. According to a study by Buelow et al. (2006) the main sources of stress related to parenting a child with epilepsy can be categorised into five areas; concern about the child, communication with healthcare providers, interaction with the school, changes in family relationships and support within the

community. It is important to reduce the effect of these stressors in order to reduce the negative impact on parenting behaviours. Rodenburg et al. (2007) suggest parents of CWE may benefit from parental training programs that would help reduce stress and modify inadequate coping behaviours. This would hopefully reduce the impact of parental stress on the CWE and consequently reduce problem behaviours. Family dynamics can contribute to problem behaviours. Issues within the family such conflict can lead to lower overall cohesiveness which is associated with higher rates of behavioural problems (McClusker et al., 2002). Other variables within the family such as emotional support can also contribute to problem behaviour. A study by Austin et al. (2004) reported more problem behaviours in children whose parents gave less emotional support and were not confident in disciplining their child. Interestingly, there are studies that report the siblings of CWE also have increased rates of behavioural problems (Hoare, 1984). This also adds to parenting stress and increases difficulties in family life. Evidence suggests siblings of CWE express high levels of concern about a range of issues; the wellbeing of their sibling, stigma attached to the condition and whether their sibling would be made fun of, not being included and their sibling being given more attention and fear about seizures including the consequences of injury and death and not knowing what to do in the event of a seizure (Mims, 1997). There is also an association between behaviour problems and parental attitude to epilepsy. Hoare & Kerley (1991) found that parents that reported higher levels of perceived stigma had children with higher levels of behavioural disturbance and depressed mood. There are a number of studies that highlight the importance of resources available to families of children with epilepsy. Generally, the less resources available to a family the more behaviour problems the CWE displays. Resources vary dependent on socioeconomic status of the family and level of parent education. Lower parent income and education

has been associated with higher levels of behaviour problems in CWE (Carlton-Ford et al., 1995). Austin et al. (2004) reported fewer behavioural disturbances in CWE with families that have more adaptive resources available to them such as family mastery and effective communication. They suggest adaptive resources are a protective factor which mitigate the development of behavioural issues.

Overall there are many contributing factors associated with behavioural problems in CWE. It is important that parents and carers are aware of the higher risk of these behaviours developing and are sufficiently supported in recognising, managing and reducing the impact of these effects on the development and general quality of life of the child. As evidenced by studies in this area, without education, awareness and knowledge of changes that need to be implemented the consequences to CWE is significant.

1.3 Cognitive Impairments

Neurocognitive impairments are frequently observed in patients with epilepsy (van Rijckevorsel, 2006). The symptoms can range from mild to severe and relate to issues surrounding learning, memory, concentration, and executive function. Children with epilepsy experience higher levels of cognitive deficit or impairment when compared to the general population (Berg et al., 2007). Mental disability is reported in 28-38% of cases (Steffenburg et al., 1996) and CWE are at least 10 points lower in IQ when matched with healthy controls (Dodson, 2001). Evidence also suggests a higher rate of comorbid learning disability in CWE (Sillianpaa, 2004). One of the most frequent cognitive impairments reported in epilepsy literature are memory deficits. CWE typically score lower than controls and normative scores in measures of memory (Menlove & Reilly, 2015; Jambaque et al., 1993). There are studies that suggest certain memory deficits are associated with specific epilepsies. Children with focal epilepsy are

reported to score lower in verbal memory measures. However, age of onset and seizure type and frequency have a significant impact on memory performance (Jocic-Jakubi & Jovic, 2006). Studies of children with temporal lobe epilepsy report impaired episodic memory (Rzezak et al., 2014). In children with GGEs, there is a reported phenomenon known as accelerated forgetting (Butler & Zeman, 2008). Patients with epilepsy frequently report memory difficulties yet perform normally on standard neuropsychological tests of memory. Blake et al. (2000) suggest epilepsy disrupts longer-term memory consolidation. Joplin and colleagues (2020) conducted a study with a sample of thirty-two children; 17 with GGE and 25 typically developing age-matched controls. They completed standardized tests of short-term memory, executive skills, and experimental long-term memory tasks. The study results indicate that deficits in long-term visual memory are present after one day, they increase over time, and may relate to reduced executive skills.

Memory issues in children are an important factor for development as they impair learning and can impact academic experience and performance. Even when IQ is controlled for, memory impairments are associated with difficulties in academic achievement (Harrison et al., 2013). Studies that have documented academic achievement in new-onset cases found no differences in the abilities of CWE and a control group at baseline. However, at two years follow up they reported children who had been experiencing recurrent seizures had a significant decline in performance (McNelis et al., 2007). Austin et al. (1998) conducted a study to compare the academic performance of CWE compared to children with asthma, another chronic illness. They found CWE to have significantly lower achievement scores than the children with asthma. They also reported boys with severe epilepsy to be most at risk of academic underachievement. The same research group also conducted a longitudinal study of

CWE and asthma to measure changes in academic achievement over a 4-year period (Austin et al., 1999). Although their results from the previous study were replicated initially, they reported no significant changes at follow-up suggesting there is no decline in academic performance in CWE over time. This was even the case for children whose condition improved. Although the exact cause of the problems is relatively unknown, there are many variables associated with academic difficulties in CWE. The findings are consistent across literature that once a child begins to experience seizures their academic performance is impaired but does not continue to decline beyond the initial deficit.

Although cognitive deficits are very common in CWE, impairments are also found on more sensitive neurological measures. Executive functioning (EF) or cognitive control refers to higher level cortical abilities such as planning, reasoning, certain aspects of attention and working memory (Pennington & Ozonoff, 1996). Development of these critical cognitive skills is crucial to successful functioning in day to day life. Without the ability to plan, learn new information or problem solve, many tasks are made much more difficult. There are also behavioural and emotional implications to poor executive functioning, adding to the factors contributing to behaviour problems reviewed in the previous section.

The neural systems involved with executive function are complex (P. Anderson, 2002). The development of executive skills occurs at varying rates during childhood and adolescence. As this is a critical time for cognitive impairments to occur, neurological illness can significantly impact maturation of executive function domains. Research suggests CWE score lower on measures of EF when compared to typically developing children and also when compared to children with other chronic illness (Conant et al., 2010). Children with new-onset epilepsy also show significant

difficulties with EF (Parrish, et al., 2007). A Norwegian study also found all aspects of EF were negatively impacted in CWE without severe cognitive deficits (Hoie et al., 2006). This applied to all syndromes groups except Rolandic epilepsy. They also reported the problems with EF contributed to difficulties in academic performance. There have been studies that have compared EF in different epilepsies. Law et al. (2017) compared the cognitive function of children with frontal lobe epilepsy (FLE) and children with temporal lobe epilepsy (TLE) and found children with TLE had more widespread neurological impairments, most notably, executive functioning. Interestingly the authors noted that when the epilepsy variables that may influence the neurological profile were examined, the greater number of AEDs correlated to poorer performance on certain factors.

There is evidence to suggest use of AEDs contributes to cognitive impairment. Many of the medications prescribed for the treatment of epilepsy have side effects linked to cognitive dysfunction (Bourgeois, 2004). Children are particularly at risk to the adverse effects of AEDs as they are more prone to adverse reactions than adults (Guerrini et al., 2012). There are various physiological explanations for differing effects of AEDs in children when compared to adults including variation in rates of metabolism, absorption and excretion which can cause adverse drug reactions (G. Anderson, 2002). There is also less research pertaining to the adverse effects of AEDs in children, as approval for paediatric use is generally delayed and permitted only after favourable results in adult populations. However, all commonly prescribed AEDs have some effect on cognitive function in children and when vital systems are involved the outcome can be considerable (Ijff & Aldenkamp, 2013). For these reasons it is essential that risk factors are identified and children who are likely to be significantly impacted are monitored to reduce any negative consequences as far as possible. However,

cognitive impairments are not an inevitability for CWE. Early diagnosis and treatment can help control seizures and reduce the impact to cognitive functions (Braun, 2017). Similarly, the effective selection and dosage of prescribed AEDs can also mitigate adverse effects (Ulate-Campos & Fernandez, 2017). There are also studies which suggest early surgical treatment options can also improve cognitive outcomes (Ryvlin et al., 2014; Lippe et al., 2010).

It is very important that parents of CWE are aware of the possible risk factors and are guided in how to identify the early signs of deficits so the impact can be limited. Support from key professionals who are able to educate and provide information is a vital resource for early intervention, possible treatment and reducing the overall impact to the child. It is imperative that access to medical specialists who can offer this type of advice and support is available to all parents of CWE so that the negative impact of cognitive impairments can be reduced as far as possible.

1.4 Mental Health Disorders

Mental health disorders in CWE are significantly higher than in the general paediatric population (Otero, 2009). In one of the first studies to document the rates of neuropsychiatric problems in children, Rutter et al. (1970) reported 7% of children in the general population and 12% of children with non-neurological physical conditions exhibited some form of mental health condition. Rates in children with epilepsy ranged from 29% for uncomplicated and 58% in those with complicated epilepsies such as structural brain abnormalities. These results have been replicated in more recent studies such as Davies et al. (2003) who had very similar findings of 9.3% in the general population, 10.6% with a chronic medical condition and between 26%-56% for uncomplicated and complicated epilepsies respectively. Evidence suggests children with epilepsy have a much higher risk of internalising problems such as depression,

anxiety and withdrawal (Rodenburg, Stams et al., 2005). Although anxiety and depression have distinctly different features that allow for separate categorisation, the two conditions tend to exist co-morbidly. As such, much of the research in this area tends to study anxiety and depression conjointly. However, as they are separate conditions with distinctive characteristics and symptomology they are each described separately in the following sections with the relevant literature that pertains to the effects on CWE.

Depression is a common and serious mood disorder. It can negatively affect how someone thinks, feels and acts. Depression is outlined in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association [APA], 2013) and requires a patient to have experienced certain symptoms over a two-week period to meet the criteria for a diagnosis. These symptoms include low mood, changes in appetite and sleep patterns, reduction in physical movement, fatigue, lack of interest and pleasure in activities, feelings of worthlessness, difficulty concentrating and making decisions. Rates of depression in paediatric populations range from 2-9% (Lewinsohn et al., 1994). However, in paediatric epilepsy, depression rates are reported as between 23-26% (Dunn & Austin, 1999). Symptoms of depression in children can be different than in adults and may present as disruptive behaviours or irritability which may be difficult to detect (Carlson & Cantwell, 1980). As some of the symptoms of depression could also be attributed and explained as symptoms of epilepsy or comorbid conditions associated with the condition, it can be hard to recognise and diagnose.

The aetiology of depression in CWE is complex. There are many neurobiological and psychosocial factors that can contribute to mood disturbances. Studies that centre around epilepsy factors have highlighted duration of illness (Oguz et al., 2002), seizure frequency (Turky et al., 2008), and seizure type (Thome-Souza et al.,

2004) as contributing risk factors. Depression has been found to be more common in adolescents with epilepsy than in children (Reilly et al., 2011). Vega and colleagues (2011) tested children with absence epilepsy aged between 6-16 years old and found much higher rates of depression when matched with healthy controls. They reported the most significant symptoms on the depression subscale were crying easily, being easily upset, sadness and social isolation reported as feeling that no-one understands them. They suggest early screening for affective disorders would help clinicians identify needs and assist with timely interventions.

Most children with a diagnosis of epilepsy are prescribed anti-epilepsy medication. In addition to seizure control, a side effect of some AEDs is that they can also change the behaviour and mood of the child and mask symptoms of depression (Eddy et al., 2012). AEDs have various mechanisms of action but the newer drugs can generally be grouped in two categories; those with sedating effects and those with activating effects (Ketter et al., 1999). Although some drugs have a mixed profile, drugs with a sedating effect are usually associated with fatigue, slowing cognition and weight gain. These types of AEDs enhance gamma-aminobutyric acid (GABA) neurotransmission and are most associated with mood changes and symptoms of depression (Mula & Sander, 2012). As such, CWE can experience treatment related depression. For this reason, it is important that patients are monitored and supported in medication management so that changes can be made if required. In some cases, it may be necessary to change or discontinue AED treatment in favour of alternative therapies.

There are many factors related to living with epilepsy that can contribute to depression in CWE. A diagnosis of a chronic illness can be a difficult adjustment. Frequent hospitalisation, unpredictable seizures and difficulties relating to treatment can cause increased stress for both CWE and their families (Conant et al., 2008). Increased

vulnerability to stress can also be a contributing factor in the increased risk of depression in young people with epilepsy (Hankin, 2006). Some studies in CWE suggest experiencing a negative life event can affect and increase the emotional and or physical response to daily stressors including increased seizure activity (van Campen et al., 2012). As seizures can occur at any time they have the potential to significantly impact day to day living. Due to this unpredictability, CWE can experience feelings of fear, loss of control and hopelessness all of which can lead to depression (Wagner et al., 2009). Studies suggest CWE have significantly lower self-concepts (Austin, 1988), and children who have a negative attitude towards their epilepsy are at higher risk of depression (Dunn et al., 1999). There is also evidence to suggest CWE experience higher levels of shame and feelings of incompetence when compared to other illnesses (Oostrom et al., 2000). Shame is felt when a person feels they are flawed and unworthy of acceptance or belonging (Brown, 2006). This is particularly relevant in epilepsy as the condition can lead to patients feeling embarrassed, self-conscious, humiliated by their condition, socially limited and vulnerable to prejudice (Chong, et al. 2016). These negative emotions, feelings and perceptions can all impact self-esteem and lead to depression. Lower cognitive function in CWE is also associated with lower self-esteem and increased depression (Austin et al. 2010).

People who suffer with both health and mental health issues can be subject to the negative thoughts or beliefs of others. These false beliefs can lead to a person feeling discrimination or stigmatised which can perpetuate the cycle of depression. Stigma, characterised as a process by which an individual experiences a loss of status and power (Link & Phelan, 2006) can be felt from both others and the one's own self-perceptions. It is generally a social process where someone is subject to "exclusion, rejection, blame or devaluation that results from experience, perception or reasonable

anticipation of an adverse social judgment about a person or group" (Weiss et al., 2006, p. 280). With regards to health conditions such as epilepsy, negative labels and discrimination in the form of stigmatization can lead to poor self-esteem, negative emotions and depression (MacLeod & Austin, 2003; Dunn et al. 1999). The associated stress from stigma or the threat of being stigmatised can also have negative consequences to mental health in terms of depression, anxiety and poor self-esteem (de Boer et al., 2008). Lack of understanding and ignorance is a major contributing factor to the misunderstandings and fears associated with this condition which leads to prejudice and stigma (de Boer, 2002). Studies in the general adolescent population such as that by Austin et al. (2002) suggest increased knowledge and awareness of epilepsy is needed to decrease stigma experienced by people with the condition. Education and proper understanding of epilepsy is also important for the families of CWE and the patients themselves. Children's understanding of their condition has been studied in various contexts and low levels of epilepsy knowledge is significantly associated with higher levels of depression (Baker et al., 2005).

Children with epilepsy are at higher risk of depression for varying reasons. They are vulnerable to illness related factors such as the neurological impact of seizures and negative side effects of medications. They struggle with the psychological burden of living with the condition including the risk of harm, medication adherence, hospitalisations and adjustments that have to be made to their daily lives. They also have to deal with the psychosocial impact of their condition and the judgements that can be made by others. All these factors increase the risk of depression in CWE. It is therefore important that they are under the care of experienced and specialist medical care providers so that these issues can be monitored and immediate care and treatment can be provided if necessary.

Anxiety is an emotion that when experienced at a disproportionate rate can impact mental health. There are a range of psychological and physical symptoms that are commonly described such as nervousness, rapid heart rate, fatigue, difficulty concentrating, digestive issues and feeling tense or fearful. There are also a range of anxiety disorders that can impact quality of life. These include obsessive and or compulsive thoughts and behaviours, fear of social situations, separation anxiety, severe anxiety following a traumatic event and persistent fear of health issues. Given the serious and unpredictable nature of epilepsy, it is unsurprising that CWE are reported as experiencing significantly higher rates of anxiety. McDermott et al. (1995) reported 24% of CWE having significant anxiety compared to 7.5% of children in the general population. Other studies such as Alwash et al. (2000) report high levels of anxiety in CWE as high as 48.5% when compared to healthy controls (16.8%). They also noted the anxiety was higher in those with poor seizure control. Williams et al. (2003) suggest epilepsy severity is associated with higher levels of anxiety and recommend monitoring of affective symptoms in children and adolescents with epilepsy. However, anxiety can be experienced in people with epilepsy in a variety of ways (Goldstein & Harden, 2000). In addition to a comorbid condition it is also associated with seizure activity. In a study that reviewed patient data from a clinic in Milan from 1990-2005, a significant number of children and adults reported that they experienced fear or anxiety in the ictal stage of a seizure (Chiesa et al., 2007). The authors suggest this is due to seizures activating cerebral networks involved in emotional experience, namely the amygdala and temporo-mesial limbic circuitry. Given this evidence it is likely that seizure activity can contribute to dysregulation of emotional circuits. Therefore, anxiety can also be a symptom of epilepsy in addition to a co-morbid condition that occurs due to having to live with the specific difficulties related to epilepsy. It is important that an experienced

clinician is able to evaluate the patient and make that distinction in relation to managing treatment.

Anxiety is one of the most frequent comorbidities found in patients with epilepsy (Verrotti et al., 2014). Studies in children with absence seizures have noted the most common symptoms reported that related to anxiety were negativity, nervousness and worrying (Vega et al., 2011). Studies in adolescents also note much higher levels of social anxiety and obsessive symptoms when compared to healthy controls (Baker et al., 2005). However, much of the literature in paediatric populations with epilepsy note that anxiety is under diagnosed and often goes untreated. Ott et al. (2003) reported 60% of CWE in a clinic based study met the clinical threshold of the DSM-IV for one or more psychiatric diagnoses. Ettinger and colleagues (1998) conducted a study of patients aged between 7 and 18-years old and found 16% met the criteria for significant anxiety symptomology although they had not been previously identified with any form of anxiety. Similarly, Williams et al. (2003) found that in a study of children between 6 and 16-years old, 23% had anxiety scores above the normal range, 5% of which were classed as moderate to severe. The implications to quality of life in CWE that experience high levels of anxiety are significant. Studies such as Stevanovic et al. (2011) suggest the impact to health-related quality of life is particularly effected in CWE experiencing generalised anxiety or separation anxiety. Other studies such as Cianchetti et al. (2018) suggest anxiety is related to lower quality of life in both CWE and their families.

As with many conditions including depression and anxiety, early recognition and treatment is an essential tool in reducing the negative impact to quality of life of both the patient and their family (Reilly et al., 2011). Many studies also suggest that psychopathology in adulthood originates from problems in childhood with respect to

psychological disturbance and therefore early detection and treatment is imperative to reduce the impact in later life (Nabbout et al., 2017; Kim-Cohen et al., 2003; Ettinger et al., 1998). For those that have severe struggles with depression or other psychiatric illness, suicidal thoughts are common. In patients with epilepsy the rates of suicidal ideation or behaviour is significantly higher than in the general population (Pompili et al., 2005). In this meta-analysis of 29 cohorts the authors calculated the mean number of suicides per 100,000 per year as 112 in people with epilepsy and 13.2 in the general population. Epilepsy is one of the few medical conditions where the increased risk is prevalent in children and adolescents as well as adult populations (Jones et al., 2003). It is also suggested that those who have longer duration of illness have significantly higher rates of suicidal ideation (Caplan et al., 2005). There is also debate as to the contribution of AEDs in the increased risk of suicide for patients with epilepsy (Ferrer et al., 2014). However, studies suggest depression and not seizure related factors or quality of life is the most likely predictor of suicidal ideation (Hecimovic et al., 2012).

Overall, children with epilepsy are at a higher risk of experiencing psychological and psychiatric problems. These issues can have a significant impact on the patients' ability to cope with and manage their condition. In order to provide suitable care, it is vital that the families of CWE have an accessible specialist medical team that can advise of these risks, educate and provide support to the families in identifying symptoms of psychological or psychiatric disturbance and are able to treat or refer the patients for immediate support and treatment.

1.5 Psychosocial Problems

Epilepsy can have a profound effect on many aspects of psychosocial functioning. Psychosocial issues for CWE relate to aspects of daily living. Typically, most of the day for a child is spent at school or at home. The most significant impact on

the family environment for a child with epilepsy are parenting factors and academic function. There are many factors that can impact and disrupt the family unit. As previously mentioned behavioural problems can have negative consequences, cognitive and learning problems can have an impact on the family and mental health conditions such as depression and anxiety can make the home environment more difficult. Studies have shown CWE can have relationship problems within the family and that quality of the parent-child relationship is a significant predictor of psychopathology in CWE (Rodenburg, et al., 2006). The same research group (Rodenburg, Meijer et al., 2005) conducted a comprehensive review of literature relating to family factors in CWE and identified distinct issues relating to quality of relationships between parent and child including parenting in terms of support and control, parenting characteristics which include beliefs and coping strategies and finally, the quality of other family relationships. They reviewed 35 studies which reported data from 1400 CWE and found that when parents of CWE were compared with parents of controls they were found to be less supportive and more authoritarian in parenting style. Mothers were found to display higher levels of emotional over involvement and overprotectiveness whereas fathers were perceived as less supportive. Parenting style relates to the emotional environment in which interactions take place between parents and their children. Typically, these environments are described in terms of warmth and control with four main categories; indulgent, authoritarian, authoritative and uninvolved parenting styles (Maccoby & Martin, 1983). The environment in which a child learns and grows is significant to all areas of their social development. As children mature the role of the parent changes. During infancy and early childhood, the type of support required is very different to that of an adolescent. A particularly important factor in the social development of children is the type of parenting experienced (Baumrind, 1971). If

parents employ a more authoritarian parenting approach such as strict rules and force it can have a negative impact on a child's social development (Mensah & Kuranchie, 2013). A contributing factor to parenting styles in the case of families of CWE is parental anxiety. Chapieski and colleagues (2005) found that mothers who display higher levels of anxiety with regards to their child's seizures were more likely to adopt a protective parenting style. Parental anxiety that is specifically related to the unpredictability of seizures can lead to overprotective parenting which can be the catalyst for social anxiety in CWE (Carlton-Ford et al., 1995). Parental attitudes to epilepsy can also have a significant impact on CWE. Negative experiences of social stigma can lead to negative attitudes towards epilepsy which if then conveyed to the child can be harmful to their self-concept (Carlton-Ford et al., 1997).

Another issue that can have a psychosocial impact on a child with epilepsy is that of the restriction of activities they are able to participate in. Parents who are more controlling and more indulgent have been found to impose significantly more restrictions on CWE (Rodenburg et al., 2013). It is important that children are able to develop autonomy and feelings of competence (Newman & Newman, 2015). By restricting activities, CWE are limited in not only the psychosocial benefits but also general health benefits from sports and exercise. Naturally, there are safety aspects to many physical activities. It may not be advisable to engage in contact sports that have the potential to injure the head or to go swimming if the child has multiple seizures each day but an experienced epilepsy consultant would be able to advise parents on an individual case basis. However, there is research to suggest some parents place more restrictions on their child than those which are medically recommended (Brna et al., 2017). This can lead to issues in the development of autonomy and can also effect their behaviour (Carpay et al., 1997). If CWE are permitted to engage in physical activities

such as sports and exercise there can be many positive benefits such as socialization, improved self-esteem and increased general long-term health outcomes (Capovilla et al., 2016). In the United States, camps for children with chronic illnesses have been created to help encourage participation in activities and facilitate social interaction amongst peers. Cushner-Weinstein and colleagues (2006) conducted a study evaluating the benefits of a camp designed specifically for children with epilepsy over a 3- year period. They reported improvements in social interaction, responsibility and communication and suggested overall continued participation in the camp over time improved adaptive behaviours.

The other major impact to the psychosocial functioning of CWE is their experience of school. CWE experience greater difficulties in schooling compared to their peers including those with other chronic illness (Austin et al., 1998). Low academic performance in CWE can occur due to a number of condition related issues. As previously outlined, comorbid cognitive and behavioural issues can have significant impact on academic performance. Other condition related issues such as seizure activity and medical appointments can significantly impact school attendance levels which in turn can increase the academic difficulties experienced by the child (Aguiar et al., 2007). Academic underachievement can have a major impact on self-esteem (Filippello et al., 2013). As children with epilepsy are at an increased risk of underachievement, they are also at risk of experiencing lowered self-esteem and poor motivation (Sturniolo & Galletti, 1994). Some studies such as that of Prasad and Corbett (2016) suggest that although self-esteem scores may vary in children with epilepsy, those who have added health impairments score significantly lower in self-esteem. As previously discussed, this has the potential to lead to depression and or a range of mental health issues in CWE. There is also research which suggests the knowledge and attitude of teachers in a

school environment can significantly impact the psychosocial development of CWE (Hsieh & Chiou, 2001). Studies in non-UK countries such as Japan, (Okumura et al., 2020) Greece, (Kampra et al., 2016) Thailand, (Kankirawatana, 1999) and Zimbabwe, (Mielke et al., 1997) have suggested that the majority of teachers have inadequate training and knowledge regarding epilepsy and largely do not know how to effectively manage the condition. Conversely, those with better education and understanding of the condition have better overall attitudes towards epilepsy. Other studies such as Bishop and Boag (2006) suggest although teachers have a significant lack of general knowledge about the condition, their attitudes towards epilepsy are generally positive. The most common finding amongst global studies in this area is that teachers lack knowledge and training in epilepsy management (Jones et al., 2018). An online survey of teachers in the US found that 68% cited the internet as their primary source of information regarding epilepsy whereas 73% would have preferred this information came directly from a physician (Mott et al., 2012). As children with epilepsy attend the full range of educational settings including mainstream and special schools, it is important that teachers are trained to manage not only the physical aspects relating to safety of the child and potential for learning problems but also the potential for psychosocial issues. Aydin and Yildiz (2007) found that teachers who engaged in epilepsy education programmes significantly changed their attitudes to be more positive towards epilepsy.

The psychosocial impact of epilepsy can be significant to CWE. For those who experience the condition throughout adolescence, the greater number of potential issues can arise due to the changes associated with this period of development. It is important that both families and educators are aware of the problems that can occur and the potential impact to the child. Education and awareness is a key factor in mitigating the

impact to CWE and helping support them through the difficulties that can arise and impact their quality of life.

1.6 Quality of Life (QoL)

Quality of life (QoL), or health related quality of life (HRQoL), is an important outcome within healthcare. Andelman (2000) defines quality of life as the individual's "evaluation of the quality of their lives as it relates to their own personal expectations" (p. 17). The International League Against Epilepsy (ILAE) (Thurman et al., 2011) stated in a report that "HRQoL can be regarded as broadest and most important outcome of any chronic health condition" (p. 12). There are many important factors to consider when assessing HRQoL including physical outcomes, psychological wellbeing, cognitive problems and social issues (Guyatt et al., 1993). The ability to identify and accurately assess these factors is especially important to patients of chronic illnesses such as epilepsy. Other medical factors such as seizure frequency, seizure severity, duration of illness and side effects of medication can have an impact on overall QoL (Ferro, 2014). There are various measures used to assess QoL in adult patients with epilepsy (Jones et al., 2020; Leone et al., 2005). However, in paediatric populations most of the measurements rely on parent-report (Ronen et al., 2003b). There are some instruments being used to measure child-reported QoL but studies are limited (Ferro, et al. 2017). An interesting study by Ronen et al. (1999) outlined the main elements of HRQoL from the patient perspective in childhood epilepsy. Through qualitative methods of analysis (Miles & Hubermann, 1994) they identified five themes which described the main concerns and burdens experienced by CWE. These included the experience of epilepsy, life fulfilment and time use, social impact, the impact of epilepsy and attribution. The authors also suggested that clinicians consider the

concepts detected as part of their routine care of CWE and their families (Ronen et al., 1999) .

A rising number of studies have documented reduced QoL in children with epilepsy when compared to the general population (Miller et al., 2003). When compared to children with asthma, CWE have been found to score significantly lower in QoL measures. Some studies report lower scores on up to 13 of 19 QoL variables when compared to similarly aged children with asthma (Austin et al., 1996). There is also evidence to suggest the onset of epilepsy in childhood can have long-term impact on HRQoL even into adulthood, especially if those adults are still on medication, regardless of whether or not they are in remission (Sillanpaa et al., 2004). There are a number of risk factors associated with decreased rates of QoL in CWE. Speechley et al. (2012) report cognitive problems as the highest risk factor of decline in HRQoL in children with epilepsy. They measured this over a 2-year period in new-onset patients. Executive dysfunction has also been associated with HRQoL with studies suggesting it is a significant predictor of poor QoL in CWE (Sherman et al., 2006). Furthermore, some studies have suggested executive deficits correlate to particular aspects of HRQoL in CWE such as emotional well-being, cognitive function and behaviour (Schraegle & Titus, 2016). There is also evidence to suggest those children with chronic epilepsy and low IQ are at higher risk of reduced QoL (Buelow et al., 2003). Studies such as that of Taylor et al. (2011) note the importance of increased support and early interventions at the time of diagnosis for both children and their family as they are at a significantly higher risk of reduced QoL. Cianchetti et al (2014) suggest parental concern regarding epilepsy and the severity of the disease correlate to the deterioration of QoL in both the child and the family unit.

Emotional wellbeing is another factor assessed in HRQoL. Measures are used to evaluate psychological functioning in order to establish whether the strain of illness is having an overall effect of the patients' emotional welfare. CWE are reported as having three times the rate of emotional problems when compared to children from the general paediatric population (Turky et al., 2008). Even when compared to children with other chronic illness such as asthma and diabetes, CWE score significantly lower in QoL and notably in measures of psychological adjustment (Moreira et al., 2013). Elliott et al. (2005) describe CWE experiencing intermittent sadness about the condition, frustration and anger directed at the number and effect of seizures and medications and fear relating to consequences of seizures. Emotional difficulties are also highlighted in parent response questionnaires that assess QoL with emotional state being reported as having a significantly negative impact on many aspects of the child's life (Malhi & Singhi, 2005). There are also illness related variables that increase the risk for poor HRQoL outcomes for CWE. Devinsky and colleagues (1999) reported that those with increased seizure severity consistently reported poor overall QoL. They also found that older adolescents (14-17 yrs) were more likely to perceive their epilepsy as having a negative impact on their general health and had more negative attitudes towards their epilepsy than the younger children (11-13 yrs) in the study. These results have been replicated in other studies such as that of Nadkarni et al. (2011) who also reported lower overall QoL in older CWE. The authors from both studies suggest this may be due to older children having more negative perceptions of their epilepsy and its impact on their lives and thus feeling it impacts their general health and overall QoL more negatively.

In addition to cognitive, physical and emotional domains of QoL, social scales are also used to measure HRQoL in CWE. In a study by Arunkumar and colleagues (2000) social problems were reported as the single most important concern about living

with epilepsy amongst CWE. They reported a variety of issues such as stigma, acceptance, embarrassment and the ability to get along with others. However, these concerns were not rated with the same importance by their parents. Interestingly, a study which relied purely on child self-report found that QoL was directly associated with peer support, parental support and mental health (Fayed et al., 2015). The authors suggest that positive daily experiences surrounding their epilepsy are linked to the child's perceived life satisfaction and that peer support should be an area of focus within child self-assessment of QoL. McEwan and colleagues (2004) conducted a systematic review of literature focusing on QoL in children and adolescents. They concluded that there is a need for studies that focus on the views of children and adolescents. Interestingly, Moffat et al, (2016) conducted a qualitative study using focus groups in CWE to establish their views of the impact of epilepsy on QoL. They highlighted two main themes which were areas of concern for CWE; "things to do with epilepsy" and "things to do with growing up". These themes had additional subthemes which suggested the social impact of epilepsy to be a particular concern, e.g. restrictions in sleepovers which had potential to effect developing friendships. The authors also noted children's concern regarding seizures and associated fears.

QoL is an important measure in healthcare as it can highlight significant cognitive, psychological, social and physical difficulties which could otherwise be missed. For people with chronic illness this is especially important as most long-lasting conditions have the potential to impact daily living. As evidenced, CWE are particularly vulnerable to the negative impact their condition and the effect it has on their everyday lives. In many adolescents the impact increases over time and has the potential to significantly affect them into adulthood. For these reasons it is important that the known risk factors are monitored by medical professionals, so that the impact can be mitigated.

With increased awareness of both professionals and the families of CWE, any support required can be accessed to alleviate the strain of daily living with epilepsy for all involved.

1.7 Psychosocial Interventions

As evidenced thus far, epilepsy can have a profound impact on children and young people who receive a childhood diagnosis. The implications on behaviour, cognitive function, mental health and quality of life have been presented. Given these implications, the ILAE have made recommendations that psychological therapies should be considered in the treatment of individuals with epilepsy to improve QoL and other associated comorbidities (Michaelis et al., 2018). Psychosocial interventions have been effective in reducing depressive symptoms (Watanabe et al., 2007), and anxiety (James et al., 2020) in CWE. Mercier and Dorris (2024), conducted a systematic review of psychosocial interventions for children and young people with epilepsy. They determined that not only is the evidence for effective psychosocial interventions for CWE growing, but also increasing in quality. They also suggested that evidence-based interventions improving mental health should be accessible early on. One such example of successful intervention was demonstrated by Dorris et al. (2017). They developed a randomized controlled trial of a psychosocial group intervention for young people with epilepsy [PIE]. The intervention involved brief therapy that could improve longer-term psychosocial outcomes. They noted that it significantly increased knowledge and confidence amongst young people with epilepsy and could serve as a model for other paediatric chronic illness groups. NICE guidelines (2022) recommend ongoing clinical discussions about the cognitive and mental health challenges children and young people face. These challenges can be associated with their epilepsy and/or their treatment. It is

important that these challenges are addressed as soon as possible to limit the impact of epilepsy on the QoL for CWE and their families.

1.8 Conclusion

In addition to their health issues, CWE are vulnerable to potentially high risk factors which can have a significant impact to development. They experience unpredictable seizures at differing levels of severity and can be subject to other difficulties in relation to their medication and treatment regimes. This can be a difficult adjustment for a child. Although there are differences in children's understanding of the implications of their condition e.g. age related understanding or limitations due to learning difficulties, a diagnosis of epilepsy can result in changes to their lifestyle and impact family activities and social interactions. In addition to the condition related issues, CWE are also at much higher risk of behavioural difficulties, cognitive impairments, mental health disorders, psychosocial problems and reduced quality of life. These can be difficult for a child to manage in addition to living with a serious chronic illness. The impact on home and school life can be significant. It is important that CWE have a support system to help them understand and manage their condition. However, the impact of living with epilepsy also extends to their parents, carers and other family members who also experience a level of burden. Parents of CWE have to manage the physical and emotional aspects of the condition as it relates to their child. The following chapter will discuss the various implications of living with a child with epilepsy and the support services available to the family, specifically Epilepsy Specialist Nurses.

Chapter Two: The Impact of Paediatric Epilepsy on Carers and the role of ESNs

2.1 Introduction

The impact of caring for someone with a chronic illness can vary greatly and the direct care needs of each patient can differ considerably (Sales, 2003). Although living with epilepsy can be a difficult adjustment for the person diagnosed, it is inevitable that there will also be an impact of living with the condition on the carers and family. There is considerable evidence to suggest the burden on parents and carers of CWE is substantial (e.g. Chiou & Hsieh, 2008; de Boer et al., 2008; Puka et al., 2018; Shore et al., 2002; Thompson et al., 2014). The burden of care associated with childhood epilepsy is multifaceted. The difficulties and challenges faced by the parents, carers, and families of CWE can result in physical, psychological and emotional consequences to their wellbeing, e.g., issues with exhaustion (Smith et al., 2014), sleep deprivation (Cottrell & Khan, 2005), increased anxiety and stress (Hoare & Kerley, 1991), higher rates of depression (Shore et al., 2002) and overall reduced QoL (Puka et al., 2018). Adaptation to illness is important in the process of adjustment following a diagnosis of a chronic illness such as epilepsy. The ways in which parents adapt to these changes and develop coping strategies to manage their stress and anxiety can have a positive effect on the way epilepsy impacts the family (Duffy, 2011). It is also important that parents are knowledgeable about the condition in order to manage it as effectively as possible. According to National Institute for Health and Clinical Excellence (NICE, 2012) guidelines, parents, families and patients with epilepsy should have access to a range of information about epilepsy including diagnosis and treatment, the impact of seizures and adequate seizure control, treatment options including side effects and risks, and the risks of injury. The role of the Epilepsy Special Nurse (ESN) has been highlighted (RCPCH, 2012; 2022) to both parents and children with epilepsy in helping to educate,

support and manage the condition. These issues, relating to the impact of paediatric epilepsy and the consequent burden of care, will be briefly reviewed in this chapter. However, with regard to the impacts of ESNs, most of the published literature has been on the adult population. There is very little research specifically addressing the contribution of paediatric Epilepsy Specialist Nurses (Appleton & Sweeney, 1995; Johnson & Dunkley, 2012; Kirkpatrick et al., 2014) and this is therefore the focus of this thesis. There are no studies that specifically compare services with and without ESNs within paediatric epilepsy services. The chapter will conclude with a brief overview of the thesis and the aims of the studies that will be presented.

2.2 Quality of Life in parents/carers of CWE

Epilepsy can have a profound effect on many aspects of quality of life for the parent/carer. Quality of Life (QoL) is an important measure in healthcare and literature was presented in the previous chapter in relation to CWE. However, there are not many studies that focus on the QoL of parents and carers of CWE which is surprising given it is an important overall measure of the various physical, psychological and social difficulties that will be presented in this chapter. Some studies such as Lv et al. (2009) and Bompori et al. (2014) have studied QoL in parents of CWE and have found they have significantly lower QoL scores when compared to healthy controls. Reilly and colleagues (2015) conducted a study of health related QoL and emotional well-being in parents of CWE in Sweden and found that parents of children with drug resistant epilepsy had much reduced QoL. Puka and colleagues (2018) conducted a systematic review of all the literature at the time in relation to QoL of parents of CWE. They concluded that parents of CWE have reduced QoL when compared to healthy controls or relative to population norms but QoL scores are similar to parents of children with other chronic conditions. However, long-term effects of epilepsy on parental QoL do

not reflect these findings. A study by the same research group (Puka et al., 2018) was the first to the author's knowledge to investigate the health related quality of life (HRQoL) in mothers of CWE 10-years after diagnosis. They reported HRQoL scores comparable to mothers in the general population which is encouraging given that the majority of studies find poorer QoL scores in parents within the first few years of diagnosis. They identified factors relating to better maternal HRQoL such as family environment and maternal psychopathology and suggested the importance of these over epilepsy related variables. The authors suggest that adopting family centred care practices and focusing on caregiver stress and the burdens associated with caring for a CWE may provide families in this population with the support required to improve and subsequently maintain overall well-being. Reilly and colleagues (2015) found QoL scores differ between mothers and fathers of CWE. They reported that mothers generally had much lower QoL when compared to fathers. This finding supports the literature reviewed in the psychological consequences section below (section 2.3) that suggests that mothers are more affected by the burdens associated with caring with a CWE as they are generally the primary caregiver in the family. In Reilly et al (2018) mothers scored higher than fathers in anxiety and lower than fathers in various mental health components on the DASS-21 which is a self-report measure of depression, anxiety and stress (Lovibond & Lovibond, 1995). The authors note there was a need to identify the best ways to support parents of CWE who present with significant mental health challenges. It is also worth noting that in addition to the research presented regarding parents of CWE a few studies have also examined the impact of epilepsy on siblings of CWE. Kroner et al. (2018) conducted a survey study to assess parental perception of the impact of their child's epilepsy on their siblings. They concluded that, according to their parents, siblings were remarkably resilient not significantly impacted

by living with a sibling with epilepsy. These findings are similar to that of Wood et al. (2008) who found that siblings of CWE are well functioning and have a good overall quality of life.

Given the overall difficulties experienced by parents/carers of CWE, the following sections will outline the impact and associated needs of the physical, psychological and social consequences of caring for a CWE.

2.3 Physical consequences of caring for a CWE

Studies have reported that parents can physically struggle with exhaustion from constantly worrying about their child and having to consistently monitor their physical health (Smith et al., 2014). Cottrell and Khan (2005) conducted a study of parental sleep patterns and adjustment to their child's epilepsy and found that in parents of CWE aged 5 and under, the average time spent asleep each night was 4.5 hours. They also reported that parents typically woke 3 times per night to check on their child. Parental sleep disruption significantly correlated to poor social, emotional and physical functioning. Hesdorffer et al. (2020) conducted a cross-sectional study using caregiver data from a Rare Epilepsy Network and found that carer anxiety and depression scores were highly associated with their level of fatigue and sleep quality. They also noted that sharing either a bed or a room with a CWE or using methods that require listening for seizures also related to poorer sleep quality. Poor sleep quality and sleep deprivation can have a significant impact on caregivers of CWE. As outlined by Gupta and Shellhaas (2020) there are a range of adverse effects including emotional, physiological, and cognitive impairments that are highly associated with fatigue and sleep disturbance. In the context of parents who are caring for CWE, they are expected to be vigilant regarding their child's seizures which then requires them to provide care both day and night. Larson and colleagues (2012) explored the effect of paediatric epilepsy on parental sleep and

fatigue and found that epilepsy severity positively correlated to parental sleep dysfunction and fatigue. They reported 69% of parents of CWE feeling concerned about nocturnal seizures and 44% stated they felt rested either *rarely* or *never*. In a focus group-based study of parents of children with severe early-life epilepsy Berg and colleagues (2018), found that in addition to seizure severity and frequency, parents highlighted the unpredictability of seizures as a major contributor to seizure/carer burden. Some examples of concerns expressed by parents included "constantly on high alert", "can never be off duty", "always having to be prepared" and "exhaustion". Parents also noted other physical complications, such as injuries to the caregiver as a result of seizures, lifting or aggressive behaviours.

2.3.1 Carer burden and need for respite

A number of studies report the impact of epilepsy on the caregivers. Thompson et al. (2014) conducted an online survey of family members of people with epilepsy, the majority of which were children. Following analysis of qualitative comments, one of the domains identified was emotional burden and the themes included stress and exhaustion, pressures on interpersonal family relationships and experiences of stigma. The authors suggest that epilepsy support services tailored to the needs of the family, specialist training for care providers and signposting to other services for financial support would help reduce the burden experienced. The burdens experienced by parents and carers of CWE are complex and have the potential to affect many areas of home and personal life. With such notable issues surrounding exhaustion in parents/carers, a likely solution to alleviate carer burden would be respite care for those families that are eligible. This would give parents and carers a break from their constant caring responsibilities and allow them time to decompress. However, these resources are limited and can take considerable time to access. Nolan & Camfield (2008), reported

that parents of children with Dravet syndrome, even with approved government funding, often waited years before receiving respite service support. Further research conducted by Freeman-Jones et al. (2024) specifically with parents/carers of children with Dravet syndrome, a severe developmental and epileptic encephalopathy (DEE), report unmet care needs, in terms of assessments, care plans and information regarding funding. These were found mostly in younger patients suggesting a need for earlier support and advice. Johnson et al. (2021) conducted interviews with parents of CWE to ascertain their views on therapeutic and educational provision. Within these interviews parents identified changes they would like to make to their child's current care provision and highlighted a need for family-focused support including increased access to respite care. Other research suggests some parents of CWE report high levels of dissatisfaction with their social lives, limitations in social activities and the need for respite from their caring role (Thompson & Upton, 1992). Parents may feel unable to go out with their own friends or participate in activities they enjoy because of the need to monitor their child's condition. Due to the unpredictable nature of epilepsy, caring for a child with a diagnosis of epilepsy can be a difficult adaptation for families to make and can give rise to a variety of challenges for both the child with epilepsy and their family which can have far reaching effects.

2.4 Psychological consequences of caring for a CWE

Beyond the physical consequences, being a parent/carer to a CWE can have psychological consequences including depression, anxiety & stress. An overview of the associated literature will be presented in the following sections.

2.4.1 Depression

Mothers tend to have primary responsibility for the care of children in the home (Gillespie & Primavera, 2000), and as such they are at particular risk of adverse

psychological impact due to their child's condition. Many studies have highlighted the significant effect of a paediatric epilepsy diagnosis on maternal depression. Ferro and colleagues (2011) found that approximately 30% of mothers of children with new-onset epilepsy were in the clinical range for depression in a self-report standardised measure. Moreover, a systematic review by Ferro and Speechley (2009) reported the risk of depression in mothers of CWE was as high as 50%. Although the reported rates of maternal depression in this population vary, other studies also support the suggestion that they are high in this population (Baki et al., 2004; Shore et al., 2002; Wood et el., 2008). Given the increased mental health risk for mothers of CWE, Ferro et al. (2011) highlight the importance of routine assessments for maternal depression in paediatric epilepsy clinics. The previously mentioned issues surrounding sleep deprivation can also result in poorer coping ability and an increased risk of depression. Wood and colleagues (2008) reported 46% of mothers with CWE having depression and 67% of the sample reported poor sleep. Thomas and Bindu (1999) found that family members of CWE reported increased levels of depression, anger and guilt. They also found that family members frequently reported feelings of frustration and helplessness associated with the child's illness. They found that 60% of parents were experiencing financial difficulties due to medical related expenditure, such as travel to hospital and drug costs. For many parents there are other financial burdens to contend with such as loss of income due to days taken as leave to care for their child during periods of illness. These unpredictable factors can add to carer burden and the associated stress which can also lead to depression and feelings of helplessness (McLaughlin et al., 2018).

2.4.2 Anxiety

Many parents of CWE experience varying levels of anxiety. Jones and Reilly (2016) conducted a systematic review of parental anxiety in childhood epilepsy and

reported that symptoms of anxiety are very common in this population, with up to 58% of parents scoring above cutoffs of standardized measures of anxiety. They suggested parental anxiety is associated with lower quality of life in CWE. There are many unpredictable circumstances that can occur in the daily life of a CWE. A qualitative study by Roberts and Whiting (2011) found parents experience feelings of worry about their child's safety and loss of control when sending CWE to school. In open-ended, semi-structured interviews, parents described feeling nervous and feeling the need to advocate for their child in a school setting especially in relation to other children's understanding of epilepsy. They reported general feelings of anxiety and uncertainty at having to give control to teachers to be their child's caregiver for the time they are with them. They discussed safety concerns about the level of first aid training in schools and a lack of confidence in how seizures may be responded to during school hours. These findings are particularly helpful in understanding the underlying everyday concerns of parents of CWE in their everyday lives and why increased levels of anxiety are experienced. A study by Williams et al. (2003) suggested that, among other factors, parents who experience increased anxiety in relation to their child's epilepsy are more likely to experience a reduced quality of life within the family. Other studies have noted a direct link between parental anxiety and the negative effect it can have on CWE for example, Dunn et al. (2010) found that higher levels of carer anxiety can have a significant negative effect on academic achievement. They suggested that treatment of parental anxiety may reduce this effect. Interestingly, an intervention study by Jantzen and colleagues (2009) found that after undertaking a family-centred educational programme to improve epilepsy knowledge, teach coping skills and encourage child autonomy, not only did the parent's epilepsy knowledge improve, their anxiety decreased and they reported fewer epilepsy related worries. Furthermore, parents

described the opportunity to share their experiences of their child's epilepsy, including traumatic elements, as very helpful. This is an interesting finding when considering the needs of parents/carers of CWE.

2.4.3 Stress

The factors associated with caring for a child with a chronic illness can cause significant increase in anxiety, stress and restrictions on family life when compared to families of healthy children (Hoare & Kerley, 1991). Stress in the family can make parenting difficult and Rodenburg and colleagues (2011) suggest this can lead to disruption in parenting behaviours and reduce parents' confidence to manage their child. Some studies suggest simply a diagnosis of epilepsy can increase parental stress regardless of condition severity and it can remain high even after follow up once the condition is better controlled (Operto et al., 2019). Parents who witness the child's first seizure can find it an extremely traumatic event. In a study that audited 269 medical records of young people with epilepsy, in 54 cases parents reported thinking that their child was dying or had died (Besag et al., 2005). Caring for a child with epilepsy is extremely stressful for the parents (Ellis et al., 2000). When compared to other chronic illness, levels of parenting stress in parents of CWE have been found to be two times greater than in the parents of children with asthma (Chiou & Hsieh, 2008). In a study of mothers with young CWE (1-7 years) 38% were found to have significant parenting stress (Reilly et al., 2018). Parenting stress is also related to negative quality of life in CWE even when controlling for illness related variables such as seizure frequency and severity (Im et al., 2019). When compared to controls, families of CWE experience significantly more stress, lower parenting confidence, issues in family functioning and relationships. It is also worth noting the two distinct categories of epilepsy as outlined by Hirsch et al. (2022). Most epilepsies are cateorgorised as GGEs however, DEEs for

example Dravet syndrome, are severe epilepsies and those children with a diagnosis can also have severe disabilities. Therefore the caring demands and subsequent psychological impact to parents/carers may be significant (Mercier et al., 2025).

Overall, the factors associated with caring for a CWE such as understanding the condition, ensuring physical safety, administration of medication, monitoring seizures, responding to unpredictable medical emergencies, ensuring social activities are appropriate, making sure all other periodic caregivers are trained and able to deal with any situation that may occur while the CWE is in their care, increase demands on the parent. Even for those not experiencing depression and/or anxiety at the level of a clinical diagnosis, the burden to parents/carer is nevertheless significant.

2.5 Social consequences of caring for a CWE

There are many complexities when considering the social impact of living with epilepsy both as the patient and as the caregiver. Camfield et al. (2001) devised an instrument to measure the impact of paediatric epilepsy on the family. They noted the various aspects of epilepsy that specifically impact the family including; the severity of epilepsy, the meaning of the illness to the child and family, the complexity of clinical management, the restriction in activities for both the child and the other family members, the coping abilities of the family unit and the level of social support and coping resources available.

2.5.1 Social impact

Some families have to make adjustments to or restrict the activities their child can be involved with. As outlined in the previous chapter, some of these restrictions are for safety and/or are medically recommended whilst other restrictions may be beyond the scope of these recommendations (Brna et al., 2017). However, restriction on activities and limiting attendance at social occasions also extends to the parents. If

parents or carers feel unable to leave their child in the care of a babysitter it can have an impact on their social lives and the activities they are able to engage with. A questionnaire study by Thompson & Upton (1992) found that 59% of parents pursued their own leisure activities less than once and month. They also found that 70 % of parents of CWE also reported not having spent one night away from their CWE in the previous year. Thomas and Bindu (1999) noted an 80% decrease in the social activities of parents following an epilepsy diagnosis of their child. These findings are consistent with Rani and Thomas (2019) who also note that parents restrict social and family activities. Parents of children with DEE also report feeling isolated after diagnosis. Specifically with Dravet syndrome, parents described distancing themselves from forms of social support, as the growing gap between their experiences and those of typically developing children and their parents, became wider (Mercier et al., 2025).

2.5.2 Social consequences

There are other factors that may impact the social lives of a family with a CWE. In studies such as Hansen et al. (2018), parents commented specifically at how they chose to “stay home” and “don’t go anywhere”. These comments were in relation to perceived social stigma of epilepsy rather than safety concerns. The authors commented how this type of social isolation and avoidance is a way of coping with the stresses associated with stigma in CWE. There is much evidence to suggest stigma is a contributing factor to the difficulties experienced within the family of children with epilepsy (Jacoby & Austin, 2007; VanStraten & Ng, 2012). Parents can feel fearful of divulging their child’s epilepsy to friends and family because they experience shame, guilt, self-blame and rejection (Rani & Thomas, 2019). This can lead to increased stress which can impact their overall wellbeing and quality of life.

Living with a child with epilepsy can have a significant impact on the entire family, in particular the parents and siblings. Ellis et al. (2000) conducted a review of all current literature at the time to examine the effects of childhood epilepsy on psychological and social wellbeing of other family members. The literature suggested that epilepsy can cause high levels of difficulties with self-esteem, marital problems and restriction of social activities for all family members. The practical implications associated with caring for a CWE extend far beyond day-to-day activities and can impact opportunities, relationships and plans for the future (Carter et al., 2022; Smith at al., 2014). As such, it is extremely important that families are able to adequately cope with the unpredictable difficulties they may experience.

2.6 Parental Knowledge

Parental knowledge of epilepsy is extremely important. Once a diagnosis has been made there are lots of elements of the condition that the family need to be aware of in order to provide suitable care for the child. McEwan et al. (2007) conducted a survey of 2000 carers in the UK which focused on quality of life in children and adolescents with epilepsy. They found that most carers of children with epilepsy had a high level of knowledge and understanding of the condition when compared to the general population. However, there are many studies with differing findings. Behrouzian and Neamatpour (2010) suggest that more education and information is needed for the families of children with epilepsy to help reduce psychological problems. They conducted a study in Iran and found a significant correlation between parental knowledge and mental health. In their sample 91.4% of parents had poor or incorrect knowledge of the condition. There have been similar findings in other international studies such as Masri et al. (2017). They conducted a study of parents in Jordan and suggest poor parental knowledge of epilepsy with only 9.3% of parents citing their

current source of information about epilepsy as their treating physician. Over 51% of parents cited the internet as their "current source of knowledge", however, over 53% of parents stated they would like to receive oral information from their clinician as their preferred choice of future information. Eighty percent of parents stated they did not feel they had enough knowledge about epilepsy. Both Zainy et al. (2013) and Gazibara et al. (2014) suggest more parental education about epilepsy is needed as many parents have significant misconceptions of the condition which can affect parenting practices. Although there may be differences in the health care systems of different countries, these studies highlight the importance of inadequate parental education of this medical condition and the impact on the family unit.. There have been studies with similar findings in Western countries, while acknowledging there may be cross-cultural differences. Nagan et al. (2017) conducted a cross-sectional telephone survey of parents/carers with newly diagnosed CWE who were being treated by a physician in Boston, USA. They found that primary caregivers have a poor understanding of the term "epilepsy" and suggested changes are needed in the way caregivers are educated about the condition. They noted that video based tools have been effective in introducing patients with low literacy levels to medical terminology (Wang at al., 2015). In an intervention study which focused on educational meetings, parents reported the need for more information and did not feel they had the knowledge or skills to help their children prior to the intervention (Buelow, 2007). However, there are studies that report parents have good general knowledge of epilepsy. Fowler et al. (2021) in a sample of mostly mothers with 80% college education, found that parents had a good knowledge of epilepsy. Overall, there seems to be a number of factors that affect parental knowledge of epilepsy, namely educational and cultural differences. These need to be accounted for when considering the needs of parents of CWE.

According to NICE (2012) guidelines, children and young people with epilepsy and their families should have access to a range of information. This includes information about; epilepsy in general, diagnosis and treatment options, medication and side effects, seizure types, triggers and seizure control, management and self-care, risk management, first aid and injury prevention, psychological issues, prognosis, lifestyle, leisure and social issues and support groups and voluntary organisations including how to access them. Educating the families of children with epilepsy leads to a greater understanding and, in turn, greater self-management of the condition. Studies such as Shore et al. (2008), suggest that educational training in epilepsy increases parental knowledge of the condition. In this study, following parental training, parents reported fewer unmet needs and were more confident in managing seizures at 6 months after attendance. It is important to note that, especially for younger children, it is generally from their parents/carers that CWE obtain their information about epilepsy. Consequently, it is important that parents provide accurate information about the condition. Lewis et al. (2010) conducted a mixed-methods systematic review of young people with epilepsy between the ages of 13-19 yrs and highlighted epilepsy information obtained from their parents or on their own carried an increased risk of misconceptions about their condition. Equally, accurate epilepsy information aided psychosocial adjustment such as clinicians demonstrating, explaining, monitoring and feeding back, and using or referring to a variety of information resources and materials e.g. books, leaflets, internet sites, etc, and referral to epilepsy charities and support groups for additional information and support.

Although adjustment to epilepsy can be difficult, it can be made more challenging if parents have a lack of understanding of the condition, are unsure or unaware of how to manage it, and are fearful because of a lack of knowledge. This can

also affect other members of the family including the child with epilepsy. Fowler at al. (2021) noted participants scored highly on the epilepsy related fears questionnaires in both short- and long-term fears. Notably they were afraid when their child was in the care of others, specifically that something might happen and their child could die during a seizure. Therefore, it is of the upmost importance that families have access to a range of information that is presented in a format they can understand, that they have the opportunity to ask questions and discuss their concerns with a trained medical professional who is able to advise them appropriately, and they are signposted to support services in their area so they can be connected with people with similar circumstances as a further source of information and social support. Increased understanding of the condition can help alleviate fears and concerns and better help families adjust to living with a chronic condition such as epilepsy.

2.7 Qualitative Research Contributions in relation to carers of CWE

Many of the challenges faced by parents of CWE have been outlined thus far, however, a large percentage of studies carry out research through quantitative methods (Chew et al., 2017; McEwan et al., 2004) and such methodologies do not capture, and consequently do not allow examination of, the reasons and explanations underlying their responses. Qualitative methods provide just that opportunity to explore participants experiences which allows for the development of a deeper understanding of the specific factors that contribute to the overall experiences (Kerr et al., 2011; Yardley & Marks, 2003). Within the field of epilepsy, qualitative research has contributed to our understanding of how CWE, their parents/carers and their families experience living with the condition (Harden et al., 2016; Yang et al., 2023). Some of these studies will be reviewed in this section.

Nguyen et al (2015) conducted a series on interviews with mothers of CWE to evaluate the cognitive and behavioural strategies employed following their child's diagnosis. Thematic analysis (TA)-was used to establish common themes in coping strategies, such as maintaining a positive outlook, re-structuring expectations and finding meaning from their experiences. These are useful findings in understanding how parents display resilience and the coping strategies adopted by parents/carers of CWE. Such understanding helps inform health care services and help shape the information and support given to the families of CWE. Employing interview techniques gave the authors unique access to the parents/carers perspective which may not have been available to them by other means. Smith and colleagues (2014) conducted a focus group with parents of CWE with the aim of understanding the challenges faced in caregiving. They used TA to identify themes relevant to parent/carers experience. Notably, "navigating the noncontingencies" was identified as the main theme and was characterised as a perceived lack of relationship between outcome and action. This spoke to the unpredictability of the condition and caregiving responsibilities. They concluded that epilepsy services would benefit from promoting "patient and family centeredness", helping parents/carers to develop self-management skills specifically around managing the condition and helping to provide links to community support. O'Toole et al. (2016) explored the challenges faced by parents discussing epilepsy related issues with their CWE. Using TA the authors identified themes relating to the communicative difficulties experienced by parents and noted the importance of healthcare professionals in supporting and educating parents.

Systematic reviews have highlighted some of the main contributions of qualitative research to this area of study (Harden et al, 2016; McEwan et al, 2004). Harden and colleagues (2016) reviewed 21 qualitative studies with the aims of

understanding the methodological concerns of including CWE in research and to synthesise the findings in order to identify common themes in the studies that were reviewed. They found that of the studies that were attempting to understand the condition from the CWE's perspective directly, rather than via a parent or carer, children with learning disabilities were often excluded from research meaning their voices are not being heard. Similarly, parental research is most often conducted with mothers as the participants so the father's experiences are not being considered. They also found that the rationale for the choice of methods was not always clear and not all studies developed the methods appropriately for use with children. They did however, propose two themes that emerged across the studies; children's agency and normalcy.

Although not exhaustive, the overview of these few studies highlight the opportunities presented by employing qualitative methods, specifically TA, has given researchers in gaining valuable insight directly from parents/carers experience and how this can inform medical services and professionals.

2.8 Epilepsy Specialist Nurses (ESNs)

The role of the Epilepsy Specialist Nurse (ESN) in the UK was developed from the early 1990s onwards (Hopkins & Irvine, 2010). Over the past 30 years the role of ESNs has evolved considerably. ESNs are now considered to be an integral part of the care team and provide a vital service. They work closely with neurologists and paediatricians with a special interest in epilepsy and spend the majority of their time in patient-related activities. ESN's responsibilities include clinical duties, education and training, management of own caseload, research and clinical audits, teaching, information management and professional development. ESNs can be the main point of contact for GPs and other care professionals, they conduct home and school visits, provide training where needed and liaise between agencies to provide consistency and

continuity of care for CWE and their families. The Epilepsy 12 Audit conducted by NICE (2012) made the recommendation that "all services without an epilepsy specialist nurse should create new posts to ensure adequate care" (p. 14). As the role of the ESN is such an integral part of the care of people with epilepsy, recommendations for epilepsy services and healthcare commissioners have been outlined by research commissioned by Epilepsy Action (2010). These include the recognition of the value of ESNs, the need to protect them from redundancy, the development of guidelines that outline the responsibilities and appropriate caseload, and to direct trusts to collect data that can be used to demonstrate the value of ESNs. In 2009 an audit was commissioned by the Healthcare Quality Improvement Partnership (HQIP) for the Royal College of Paediatrics and Child Health (RCPCH) to establish Epilepsy12. Epilepsy12 is an ongoing, long term clinical audit of healthcare for CWE with the clear aim of helping to improve the quality of care for young people with epilepsy in the UK. When the first round of the Epilepsy12 audit was published (NICE, 2012) only 53% of trusts had ESN provision and many children had no contact with an ESN within the first 12 months of assessment (RCPCH, 2012). These figures have improved over the past decade with recent reports showing up to 76% of newly diagnosed children and young people receiving support from an ESN within the first year of diagnosis (RCPCH, 2022).

2.8.1 Training and experience

ESNs are highly experienced and qualified specialists. Most specialist nurses are now required to have or be working towards some level of postgraduate education such as a postgraduate certificate, diploma or a Masters in advanced practice (Royal College of Nursing, 2013). They complete specialist paediatric epilepsy training (PET) up to level three which has been developed by the British Paediatric Neurology Association (BPNA), the professional organisation for doctors who specialise in the care of children

with neurological disorders. Level one covers acute and community care and is aimed at any health professional involved in the care of children with epilepsy. Level two targets secondary management and is specifically designed for paediatricians, trainees and ESNs to help develop further expertise in childhood epilepsies. Level three continues to develop knowledge in secondary management but with a focus on mid-childhood, older children and adolescents. This expert knowledge enables ESNs to take on many of the same responsibilities as a consultant. They are able to perform drug reviews, clinical assessments and provide information about the condition. The main activities they do not perform, which are only carried out by the consultant, relate to diagnosis and the ordering and interpretation of diagnostic tests. By providing such an array of specialist services to patients and carers, ESNs are able to reduce the amount of time the consultants need to spend with the patients, freeing up consultant time for more complex cases. They are able to provide a high level of support to patients as they build close relationships and are able to understand their needs. They are a main point of contact if a patient has queries or requires additional support and can act as a liaison with schools, nurseries and any service a child may attend including respite, which helps maintain continuity of care. Parent/carer support provided by an ESN includes; care planning, risk assessment and telephone advice. These are essential services that help the children and families affected by a diagnosis of epilepsy. They provide a specialist level of knowledge that is not available from a general practitioner (GP). ESNs also provide support in transition from paediatric to adult care. This is an integral part of the service ensuring the purposeful and planned move of young people to adult care. It occurs during a critical period of development and is potentially impactful on the patients future (Carrizosa et al, 2014). ESNs are able to support with transition to adult services and can handover to adult ESNs in areas with access to this type of

support. However, past reports found that only a third of trusts had transition services in place (Epilepsy Action, 2009) though this has now increased to 65% (RCPCH, 2022).

Despite the outlined benefits, there is limited research that adequately evaluates the impact of ESNs in paediatric services. Historically the evaluation of ESN services as part of the care team have focused exclusively on adult services. In these studies, the examined outcome measures have been clinical (Ridsdale et al., 1999; Risdale et al., 2000; Warren et al., 1999), patient satisfaction (Helde et al., 2005; Mills et al., 1999), measures of patient knowledge (Ridsdale et al., 2000; Warren, 1999), and patient quality of life (Helde et al., 2005; Mills et al., 1999).

2.8.2 Clinical measures

In terms of clinical measures, Ridsdale et al. (1997) found that patients seen by the ESN were three times more likely to have had their plasma concentrations of anti-epileptic medication checked relative to usual care. No differences between ESN and no-ESN areas have been found in seizure frequency and levels of depression, a comorbidity of epilepsy (see review in Meads et al., 2002).

2.8.3 Patient satisfaction

Measures of patient satisfaction have been mostly positive in studies evaluating the contribution of ESNs. Mills et al. (1999) found that accessing ESNs increased patient communication and increased the provision of information and advice for patients. In a later study, Mills et al. (2002) found that patients were more likely to want to see an ESN if they were dissatisfied with their current epilepsy care and reported being very satisfied with the service offered by ESNs. Ridsdale et al. (2003) conducted and interview study of patients with epilepsy, including young people and suggested they highly value the time and explanations given by ESNs. However, there are very few studies that assess patient satisfaction with epilepsy services in children. A

systematic review by Weibe et al. (2014) found only 8% of the studies they reviewed involved CWE and none of those looked at satisfaction with ESN care. More research in this area is needed.

2.8.4 Patient knowledge

In relation to patient knowledge, Ridsdale et al. (2000) found that in newly-diagnosed epilepsy, although there was no overall significant difference in knowledge scores between groups with and without ESN care, there was a significant increase in knowledge in patients with fewer years in education in the ESN group relative to baseline. Warren et al. (1999) also reported no difference in knowledge in people with established epilepsy between ESN and no ESN groups. However, Pfäfflin et al. (2016) in a randomised control trial of epilepsy patients, found that the ESN group significantly improved in epilepsy knowledge in comparison to the control group.

2.8.5 Quality of life

In terms of studies assessing quality of life (QoL), several studies report no significant differences between ESN and no ESN groups (Mills et al., 1999; Warren et al., 1999) with one Norwegian study reporting a small increase in QoL in the ESN group relative to baseline, with no corresponding increase in the group without ESN care (Helde et al., 2005). Evaluations of patient satisfaction have generally yielded results in favour of ESN intervention groups. Helde et al. (2005) using a single question about general satisfaction, with a visual 10cm analogue scale from “very unsatisfied” to “very satisfied”, obtained a highly significant difference in favour of the ESN intervention. Scambler et al. (1996) and Ridsdale et al. (2000) report ceiling levels of satisfaction in relation to nurse ratings (median score of 5 on a 5-point Likert scale) in an ESN intervention group, and these scores were higher than the ratings given to other professionals on the non-ESN intervention group, although no statistical analyses are

reported. Ridsdale et al. (2000) also found that significantly more people in the ESN intervention group reported that they had sufficient information on key topics relative to the non-intervention group. Warren et al. (1999) did not find differences in satisfaction levels in their study.

2.8.6 Recent adult ESN studies

More recent studies in adult populations, such as Ek Hauge et al. (2020), report patients with epilepsy who are followed-up with ESN support in a hospital setting are better informed about epilepsy related topics, such as diagnosis, anti-epileptic drugs (AEDs), routine use of AEDs and seizure related injuries. They suggest this may be due to the additional time ESNs allocate to individualised patient education compared to the time able to be given by medical doctors. They also highlight the ESNs' ability to explain complex medical information so that is clear and accessible to all literacy levels. They noted this does not always occur with more senior medical professionals and the literature given to patients can be well above their literacy level. Locatelli et al. (2021) conducted a mixed method study of the roles and activities of ESNs and note the "truly holistic care" given to patients and their carers in regard to their social, emotional and clinical needs. Their findings also highlight the leadership role of the ESN in guiding both people and processes.

2.8.7 Evaluation of paediatric ESN services and rationale for thesis

In 2019 Campbell and colleagues conducted a systematic mapping review with the aim of providing an overview of published literature relevant to ESNs which would evaluate the effectiveness and impact of their role on services, patients and their families. Their inclusion criteria were broad and included all types of research designs, audits and also some opinion pieces. Overall, they included 96 papers in the review. Only a couple of studies focused on children with epilepsy and or their families. The

majority of the research they found examined adult populations but also included GPs (Macdonald et al., 2000), school nurses (Terry., 2016), school teachers (Mott et al., 2013), ESNs (Hopkins et al., 2012), and other healthcare professionals (Varley et al., 2006). Overall they concluded ESNs are highly valued by their patients, the patients' families and by other healthcare professionals. Many of the studies highlighted the range of support they offer and perceived improvements in the care of people with epilepsy. In particular, their specialist knowledge and accessibility was found to be key to their value. Most studies were unable to demonstrate improvements in certain outcome measures such as reduced seizure frequency, however, it could be argued whether seizure frequency is an appropriate outcome measure of the effectiveness of paediatric ESNs, given that some epilepsies are pharmacoresistant. Campbell et al. (2019) also noted certain elements of the ESNs role which were poorly recognised, namely as a point of contact for patients and carers, and their liaising with and linking of services. They also commented that although elements of the ESNs' work with children is described, there is a lack of evaluation on the impact of that particular type of care.

Williams et al. (2018) is another key study in the evaluation of paediatric epilepsy services. As part of the Epilepsy 12 audit (see section 2.8) they conducted a survey of over 2300 parents and young people from 192 paediatric units about their experience of epilepsy services. To date, it is the largest patient self-report study to survey children and young people's experience of epilepsy services. Four concerns were identified. Decreased levels of satisfaction were reported if; parents expressed they had not received information about their child's epilepsy, they experienced difficulty when trying to contact the epilepsy service, parents believed staff did not make it easy for them to attend the clinic, and if parents felt they did not have enough clinic

appointments. The strongest factor influencing satisfaction score was the perceived ease of contacting services, potentially an advantage for services with an ESN.

2.9 The Thesis

The aim of this thesis is to address the significant gaps in literature, as identified above, in relation to paediatric Epilepsy Specialist nurses (ESNs). This will be approached from the perspective of the parent/carer. The main purpose will be to identify those aspects of the ESNs work that are perceived as most valuable to families of CWE.

In the first study (see chapter 4), a questionnaire will be administered regarding the carers needs for information and their experience of the epilepsy service. Responses from areas with and without an ESN will be compared to establish whether there are significant differences in carer needs and their experience of service provision. We hope to answer the following research questions;

- Are there are any significant differences in measures of satisfaction in areas with and without an ESN?
- Are there significant differences in the ongoing/remaining needs of carers/parents of CWE in areas with and without an ESN?
- Are there any significant differences in measures of accessibility between areas with and without an ESN?

The second study will be a thematic analysis of a large number of interviews conducted with parents/carers of CWE (see chapter 5 & 6). These semi-structured interviews cover a wide range of topics through from when they first perceived something was wrong, diagnosis, current challenges and thoughts and concerns for the future. The participants had the unique opportunity to discuss their personal circumstances and the specific challenges they face. The aim will be to better

understand these challenges, the interactions the families have with the epilepsy service and how they perceived the support they received. Overall, it is hoped that this research will give important insight from the carer perspective which will help identify the most valuable aspects of the work of paediatric ESNs based on carer experience, using both quantitative and qualitative methods.

In the following chapter, the sample and recruitment process for both studies will be presented. This includes descriptions of the NHS trusts involved in the study, an overview of the background of each of the ESNs, sample identification and recruitment, and the demographic and clinical information of the participants and their children. In chapter 4 the questionnaire study will be presented including an evaluation of the measures available and chosen for the study. Chapter 5 will outline the methodology for the interview study including choice of qualitative analysis. Chapter 6 will include the analysis of the interviews outlining and discussing each theme that was generated. Chapter 7 will form the general discussion of the thesis findings.

Chapter Three: Sample and Recruitment

There are two main studies in this thesis; firstly, a questionnaire study which will be reported in the chapter 4 and then chapters 5 and 6 will report the results of a large interview study analysed using qualitative thematic analysis. Most of the people that participated in the interviews also completed the questionnaires (88%). Around half the people that completed the questionnaire also completed the interview (53%). In this chapter, full descriptions of the service models from different areas, together with recruitment and sample information, will be provided. The following chapters will include methods sections with further information relating to measures and procedure which will be study specific.

3.1 NHS Trusts

There were five NHS trusts in the North-West of England involved in the study. Due to time and travel constraints, part of the inclusion criteria for the studies reported within the thesis was that the trusts would need to be in the North-West of England as the research base was at Lancaster University. An additional inclusion criteria was that all areas needed to have a consultant paediatrician with a special interest in epilepsy. Initially, two ESN areas were recruited to the project by the research team. Once the project had ethical approval it was adopted by the NIHR CRN (National Institute for Health Research Clinical Research Network portfolio) under the Children's network. As part of the clinical research network, co-ordinators were able to identify potential trusts that would be suitable and make contact on behalf of the research team. Specialist research nurses (henceforth referred to as "research nurses") aided with patient identification, recruitment, and clinical information-gathering. With this help three other trusts were identified. The researchers conducted meetings with the research nurses for each area to discuss the study protocol, explain what the study entailed and what help

was needed from them and to answer any questions. Once the study was reviewed and approved by the clinical lead for the area (which in each case was a consultant paediatrician with a special interest in epilepsy) the trust was recruited to participate in the study. Overall, three areas had Epilepsy Specialists Nurses (ESNs) and the other two did not have a dedicated ESN within the paediatric epilepsy service. For the purposes of anonymity these areas will be referred to as Area 1-ESN, Area 2-ESN, Area 3-ESN, Area 4-NoESN and Area 5-NoESN for the entirety of this thesis.

3.1.1 Area 1-ESN

This was the first area recruited to the study and to receive REC approval to commence recruitment in November 2014. Due to a non-substantial amendment that was subsequently submitted to make a minor change to the participant recruitment process (see recruitment section for further explanation), recruitment for this area was paused until February 2015 once all permissions had been granted. This area had a full-time, dedicated ESN (see Table 1 for further details of training, workload and role remit for all ESNs in this study). There was no ESN for the trust prior to the current ESNs appointment. Within this trust, paediatric epilepsy patients (caseload = 225) are seen by a consultant paediatrician with a special interest in epilepsy or by a member of their team who would present the case to the consultant at a briefing at the end of the clinic session. This trust had dedicated epilepsy clinics (as opposed to mixed paediatric clinics) where patients with a firm diagnosis of epilepsy or patients awaiting diagnosis would be seen. The ESN routinely attended these clinics and was present during consultation appointments with the parents/carers and paediatric patients. The ESN also ran yearly Quality of life (QoL) clinics with the parents/carers and patients separate from the consultations and without the consultant in attendance. These clinics offer the parents/carers an additional opportunity to discuss all aspects of managing the

condition. Additionally, the ESN in this trust liaised with ESNs from adult services and held regular transition clinics for those patients of an age where their care would soon move on from paediatric care to adult services to help prepare them for this change. This service has been highlighted as a model of good, holistic clinical practice (Martland & Cross, 2009).

3.1.2 Area 2-ESN

The next area recruited to the study was an area with an ESN (see Table 3.1). Recruitment for this trust also began in February, 2015. The ESN in this service worked 50% of their time for the Epilepsy Service as they have additional responsibilities elsewhere. The trust has some dedicated epilepsy clinics but patients are also seen in general paediatric clinics for their appointments. There are a number of consultants with a special interest in epilepsy that see patients (caseload = 180). The ESN attends some of these clinics. There were no dedicated QoL or transition clinics at the time of this research being conducted. There was no ESN in this area prior to the current ESNs appointment.

3.1.3 Area 3-ESN

This was the final site recruited to the study and participant recruitment began in August, 2015. This trust has a dedicated ESN who works full-time within the epilepsy team (see Table 3.1). There are dedicated epilepsy clinics with special interest consultants. The ESN attends some of the clinics with prior arrangement and based on clinical need. At the time of this study the ESN had only been in post approx. 18 months and hadn't yet seen all the patients on the caseload (caseload = 180). This meant there were some patients they worked with closely and others who were not known to them at all at the time of data collection. There was no ESN in this area prior to the current ESNs appointment.

3.1.4 Area 4-NoESN

Recruitment began in this trust in March, 2015. Historically this trust had a community nurse that worked in an ESN capacity. When they retired no ESN was appointed. During the early stages of this project a trainee ESN was appointed, however, they also worked on the Children's ward full-time so could only attend some clinics. When they were in attendance of clinic appointments they took notes for the consultant and observed the consultation, but did not otherwise contribute to the consultation. The trainee was in the process of gaining further qualifications in paediatric epilepsy care. In this trust there was a consultant with a special interest in epilepsy and paediatricians with epilepsy patients on their caseload (caseload = 70), and no epilepsy-only clinics.

3.1.5 Area 5-NoESN

This area was recruited to the study in July, 2015 and was the final trust without an Epilepsy Specialist Nurse. During the course of the study they did start the recruitment process for an ESN. Until this point non specialist community nurses had acted in a similar capacity, providing support for some of the patients. There were two consultants with a special interest in epilepsy that ran mixed clinics for their patients (caseload = 93).

3.2 Epilepsy Specialist Nurses (ESNs)

There were three different ESNs involved in this study from three separate NHS trusts. An overview of their experience and training is outlined in Table 3.1.

Table 3.1

ESN experience, training and role remit

	Area 1	Area 2	Area 3
Band	7	6	7
Years in role	9.5	2.5	1.5
Training	Diploma in Epilepsy Care, PET[a]1, PET2	Degree modules in the Care of people with epilepsy[b]	PET1, PET2, PET3
WTE[c] Epilepsy	1.0	0.5	1.0
Prescriber	Yes	No	No

[a]PET = Paediatric epilepsy training (full explanation given in the ESN section of Chapter 2). [b]Care of people with epilepsy is a graduate certificate course which is also offered as degree modules by arrangement. [c]WTE = Whole time equivalent of 37.5 hours worked per week.

3.3 Ethics

Ethical approval was given by the NHS Research Ethics Committee (REC) in August, 2014. However, the original recruitment plan was for the research team to contact all patients who met the inclusion criteria and for them to opt-out of the study. Once individual trusts were recruited to the study the local teams reviewed the paperwork and it was decided that the protocol be changed to an opt-in strategy and the research nurses contact the patients about the study directly. Due to the nature of this change in protocol and the changes needed to the patient facing documents, a non-substantial amendment was submitted in November 2014 and approval for the study to begin recruitment was granted in February 2015.

3.4 Sample identification and recruitment

Potential participants for the studies were identified by the research nurses of each of the NHS trusts recruited to the study. They conducted a search of patient

records on an in-house database which contained the medical records of patients on the caseload of paediatric clinicians to identify patients with a firm diagnosis of epilepsy. The main exclusion criteria for this study was for those patients already recruited to SANAD II (a national drug study that was recruiting newly diagnosed patients) as this study required a lot of follow up. After seeking advice from consulting clinicians it was decided that it would be too time intensive for participants to be involved with both studies concurrently. Also, those who did not speak English fluently were not able to participate in the interview component of the study as there were not resources available for translation services. Exclusion also included looked after children i.e. those in foster care, due to child protection, data protection and consenting issues. From the search of patient records the research nurses were able to highlight patients that fell under these exclusion criteria and identify suitable candidates (see Figures 3.1 and 3.2).

Parents/carers were recruited by way of an invitation letter sent directly from their local epilepsy team. This was then followed up where possible by telephone contact from a research nurse. Those patients who received the information packs but had not returned the consent forms were then approached in clinic and consented on the day of the appointment if they chose to participate. Originally there were three components to the study; recording of a consultation with a paediatrician, a questionnaire and a semi-structured interview. Maximal flexibility was given to the participants so that they could opt in or out to any of the three components at any point during the study, e.g. a participant could opt in to the questionnaire only part of the study and later decide to participate in the interview as well. Due to the low number of consultation recordings in areas without an ESN (n = 5), as well as the richness of the interview material generated, the consultation data will not be reported in this thesis.

To maintain a level of consistency with the length of time that each participant had last had contact with the service, the anchor point for the study was the date of the next consultation appointment. This was either the 3-, 6-, or 12-monthly routine check-up for children with well controlled epilepsy or the next appointment for those who are seen more often due to the severity or complexity of their condition. Approximately two weeks after the appointment the questionnaire was sent out in the post to the participant. This is a brief validated measure which assesses psychosocial care needs of parents/carers of children with epilepsy, including a subscale about satisfaction of clinical consultations, and remaining needs for information and support (Austin et al., 1998). Those participants who had consented to an interview were typically contacted by phone by a member of the research team within a month of their consultation appointment and arrangements were made for a researcher to come out to their home to conduct a semi-structured interview (see Figure 3.3 for mean time between consultation and interview appointment for each area). These interviews varied in length (dependant on the participants' experiences) but generally lasted an hour. Further information regarding the measures and interview structure will be given in the later chapters.

The PRISMA diagrams in the figures below (Figures 3.1 & 3.2), show the numbers of participants identified from each caseload and process of identification of eligibility and subsequent consent to the research. The overall percentage of patients on the caseload eligible for the studies ranged between 61-93%. The number of participants who consented the questionnaire study ranged between 15-35% however, overall participation in the questionnaire study ranged between 5-23%. The reasons for this discrepancy are somewhat unknown. According to Fincham (2008), response rates of 60% should be the goal of researchers in most questionnaire research. The overall response rate for all five areas combined was 52% however, the range was between 33-

94% so was quite different across areas (see Table 3.2). In an attempt to ascertain why there were such differences in response rates the socio-economic status (SES) for each area was calculated for those that were sent the questionnaire and did not return it and for those that responded. This was the only information obtained for all consenting parties in the questionnaire study. However, on closer inspection there was insufficient data to conduct any statistical tests. The SES data for each area is also detailed below in Table 3.2. There are no obvious differences between those who returned the questionnaire and those who did not, but there is no further information to compare. Every effort was made to increase response rates for the questionnaire study. Contact was made with people who did not return the questionnaires in the form of text reminders sent to their mobile telephones and for those that still did not return the initial questionnaire, a second copy was posted with a hand written note as suggested in Edwards et al. (2009).

For the interview study the percentage of participants who consented ranged between 6-25% of those on the caseload. However, overall participation in the interviews ranged between 3-23% of the caseload. Of those that consented to be interviewed 67% completed the interview overall. The range of those that completed the interview by area was between 58-100% (see Table 3.3). The overall participant loss was n = 28. The data loss from participants not completing the interviews were for two main reasons. Firstly, there was difficulty contacting some of the participants to arrange an appointment n = 21 (75%). Contact telephone numbers were listed on the consent forms and researchers called the participants directly to schedule interviews. In some cases calls were not answered. Although several attempts were made to contact the participants including voice messages left on answer machines it was not possible to speak to some of the participants to make any further arrangements for them to

participate in the research. The other main reason for data loss was due to some of the participants cancelling the interview appointments n = 7 (25%). The reasons given were due to illness, medical appointments and other personal circumstances but they did not wish to re-schedule the appointment so the interview could not take place. There were also 2 no-show incidences where the researcher arrived at the participants home to conduct the interview but the participant was not there and no further contact could be made. Full breakdown by area of data loss is given in Table 3.3. The SES of participants who completed interviews and those who did not is also given in Table 3.3. As with the questionnaire sample, there was insufficient data to conduct any statistical analysis. There are no obvious differences between the groups and no other information to compare.

Table 3.2

Participant response rates and SES of respondents and non-respondents of questionnaire

	Area 1-ESN	Area 2-ESN	Area 3-ESN	Area 4-NoESN	Area 5-NoESN
Response rate, *n* (%)	37 (53.62)	9 (33.33)	23 (58.97)	16 (94.12)	11 (33.33)
Socioeconomic status of respondents, *n* (%)					
SES[a] Upper third rankings	19 (51.4)	5 (55.6)	12 (52.2)	-	4 (36.4)
SES Middle third rankings	5 (13.5)	1 (11.1)	4 (17.4)	11 (68.8)	2 (18.2)
SES Lower third rankings	13 (35.1)	3 (33.3)	7 (30.4)	5 (31.3)	5 (45.5)
Non-response rate, *n* (%)	32 (46.38)	18 (66.67)	16 (41.03)	1 (5.88)	22 (66.67)
Socioeconomic status of non-respondents, *n* (%)					
SES[a] Upper third rankings	24 (75.0)	13 (72.22)	12 (75.0)	1 (100)	17 (77.27)
SES Middle third rankings	1 (3.13)	3 (16.67)	2 (12.5)	-	4 (18.18)
SES Lower third rankings	7 (21.88)	2 (11.11)	2 (12.5)	-	1 (4.55)

[a]Socioeconomic status (SES) derived from the Indices of Deprivation rankings for postcode areas in England 2019.

Table 3.3

Participant interview completion rate and SES of interviewees and non-interviewees

	Area 1-ESN	Area 2-ESN	Area 3-ESN	Area 4-NoESN	Area 5-NoESN
Interview completion rate, *n* (%)	17 (54.84)	6 (60.0)	14 (63.64)	16 (100.0)	5 (83.33)
Socioeconomic status of interviewees, *n* (%)					
SES[a] Upper third rankings	10 (58.8)	2 (33.3)	9 (64.3)	1 (6.3)	2 (40)
SES Middle third rankings	3 (17.6)	2 (33.3)	2 (14.3)	11 (68.8)	-
SES Lower third rankings	4 (23.5)	2 (33.3)	3 (21.4)	4 (25)	3 (60)
Non-completion rate, *n* (%)	14 (45.16)	4 (40.0)	8 (36.36)	-	1 (16.67)
Socioeconomic status of non-interviewees, *n* (%)					
SES[a] Upper third rankings	8 (57.14)	3 (75.0)	5 (62.5)	-	1 (100.0)
SES Middle third rankings	2 (14.29)	-	1 (12.5)	-	-
SES Lower third rankings	4 (28.57)	1 (25.0)	2 (25.0)	-	-

The following PRISMA flow diagrams depict the overall identification and recruitment process for each of the five areas.

Figure 3.1

Identification and recruitment of participants for questionnaire study

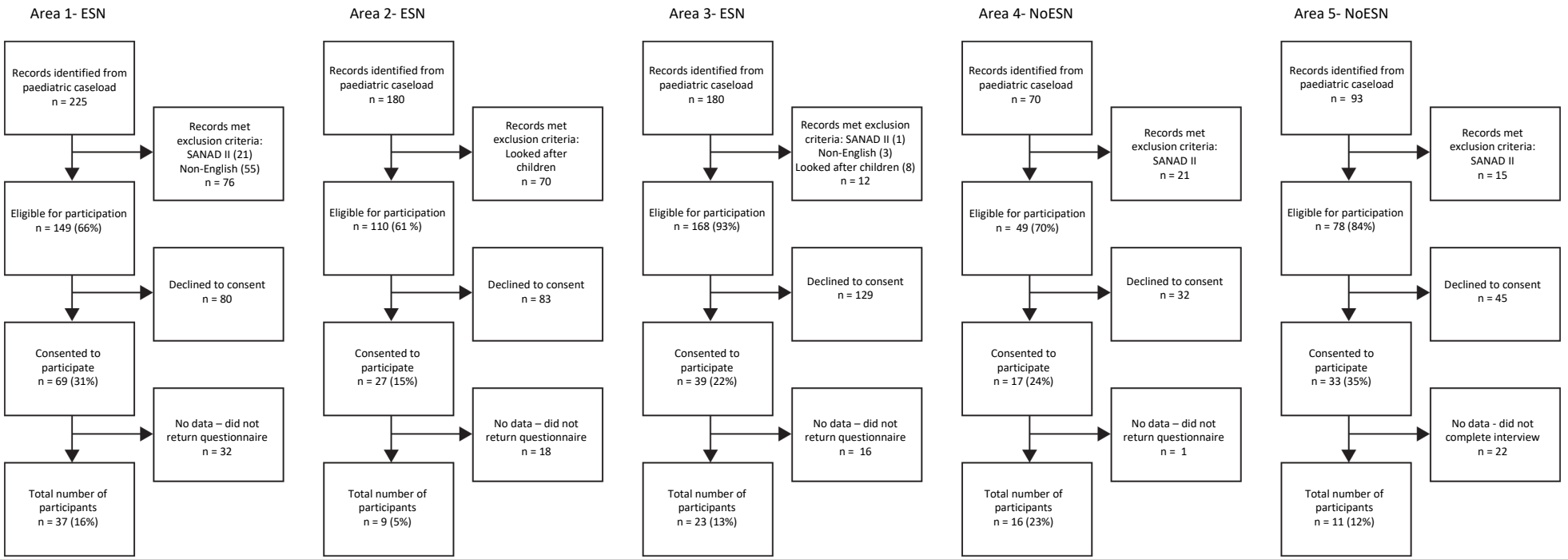


Figure 3.2

Identification and recruitment of participants for interview study

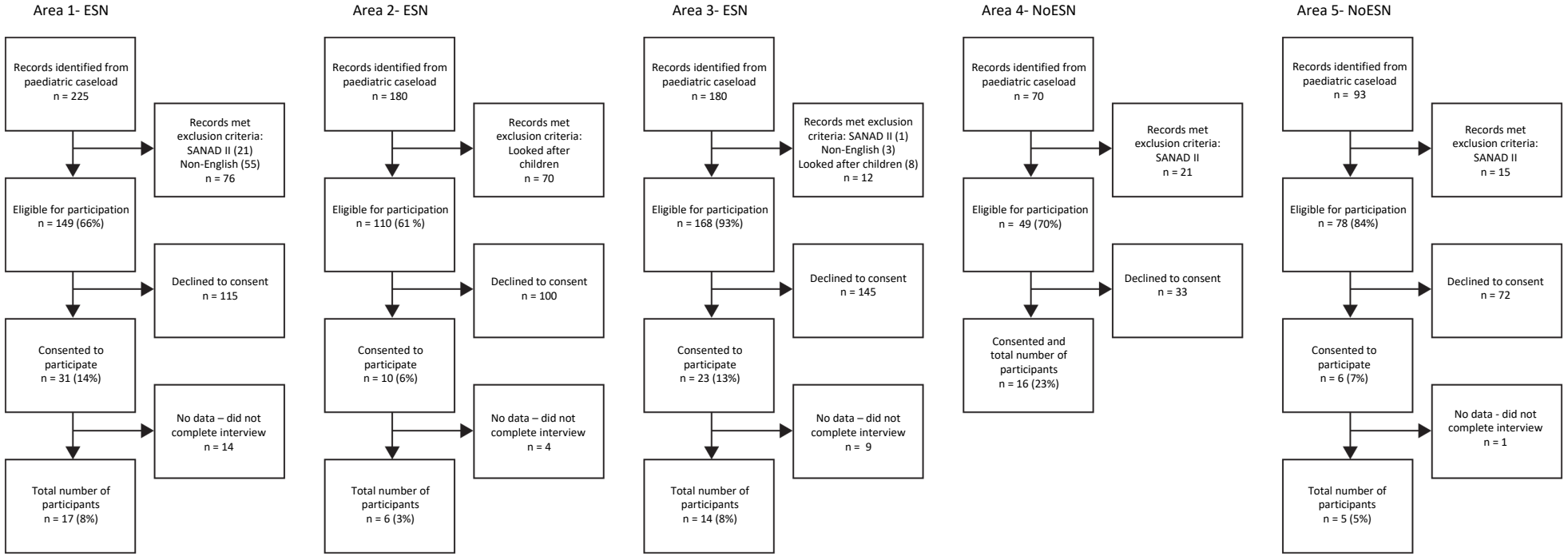
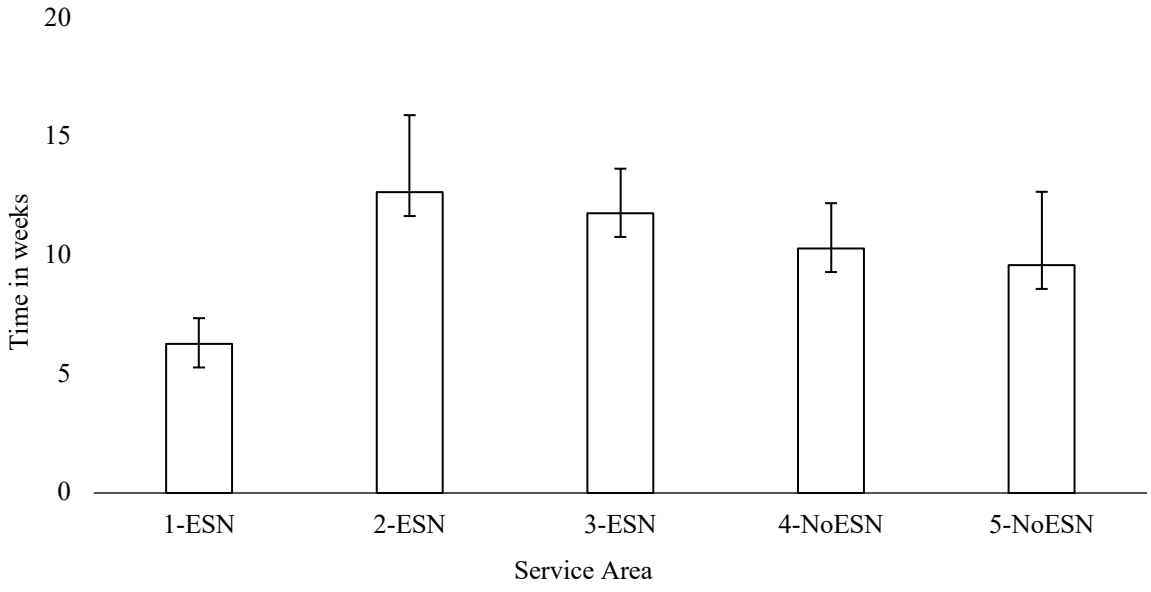


Figure 3.3 shows the mean time in weeks between consultation appointment, the anchor point in the study, and when the interview was conducted. As additional trusts were recruited to the study the researcher had a higher volume of interviews to conduct so the time frame between consultation and appointment increased. This is why the average time is less in the first area than the others. Additionally, there was scheduling conflicts with participants e.g. they would receive a last minute medical appointment or their child became ill and they needed to re-schedule. This also caused a bigger delay between consultation and appointment. However, these issues were consistent across all areas. An analysis of variance (ANOVA) confirmed the average time between consultations and interviews across areas was not significantly different $F(1, 56) = 2.3$, $p = .13$, $\eta_p^2 = .04$

Figure 3.3

Mean time in weeks between consultation appointment and interview by area



3.5 Participants

Participants were the parents/carers of children with a diagnosis of Epilepsy and who were on the caseload of consultant paediatricians in the Epilepsy service of

five NHS trusts in the North-West of England. There were 96 participants in the questionnaire study and 58 for the interview study. Demographic and clinical information will be reported below for each NHS trust for each study (questionnaire and interview) below (Tables 3.4-3.7).

There are a number of similarities between participant groups (see Tables 3.4 & 3.6). Firstly, the majority of participants (between 88-100% for both questionnaire and interview studies) were mothers of CWE. Also, the overwhelming majority of participants declared their ethnicity as white British (between 82-100%). For the questionnaire study the mean age was 39 years, 1 month. In the interview sample the mean age of participants was 39 years, 11 months. In tables 5 and 7 the clinical information for the CWE is reported. This information was collected by research nurses working in each of the five areas. They all completed the same questionnaire template for each patient which was developed by the consultant collaborators working with the research team on the study. The information was extracted from the trust's internal database which included access to medical notes and letters from the paediatricians. The records were also independently checked by a paediatric neurologist (emeritus) who helped with the classification of seizure type, epilepsy type and aetiology of each patient.

Overall, the CWE in the questionnaire sample were 59.4% male, with a mean age of 9 years (see Table 3.5 for breakdown by area). In the interview sample the CWE were 65.5% male, also with a mean age of 9 years (see Table 3.7 for breakdown by area). There does not appear to be any major differences in seizure type or epilepsy type across areas for both studies however, there is not sufficient data to conduct statistical analysis for comparison. It does appear that Area 4-ESN has more complex cases than the other areas given the higher level of epilepsy syndromes and

comorbidities in the sample but more data would be needed to evaluate whether this difference is statistically significant. Possible implications will be discussed in subsequent chapters.

Questionnaire Sample

Table 3.4

Demographic data of participant carers of CWE

	Area 1-ESN (*n* = 37)	Area 2-ESN (*n* = 9)	Area 3-ESN (*n* = 23)	Area 4-NoESN (*n* = 16)	Area 5-NoESN (*n* = 11)
Relationship to child, *n* (%)					
Mother	34 (91.89)	8 (88.89)	22 (95.65)	16 (100)	10 (90.91)
Father	3 (8.11)	1 (11.11)	1 (4.35)	-	1 (9.09)
Age, y:mo					
M (*SD*)	38:6 (6:10)	42:5 (9:0)	37:2 (7:4)	40:11 (8:1)	39:9 (4:3)
Ethnicity, *n* (%)					
White British	32 (86.5)	7 (77.8)	20 (87.0)	16 (100)	10 (90.9)
Asian British	5 (13.5)	2 (22.2)	2 (8.7)	-	1 (6.3)
Declined to answer	-	-	1 (4.3)	-	-
Yrs of Post-16 Ed					
M (*SD*)	2.68 (2.4)	2.00 (1.58)	2.26 (2.12)	2.44 (2.19)	2.91 (2.88)

Table 3.5

Clinical features of CWE

	Area 1-ESN (*n* = 37)	Area 2-ESN (*n* = 9)	Area 3-ESN (*n* = 23)	Area 4-NoESN (*n* = 16)	Area 5-NoESN (*n* = 11)
Gender, *n* (%)					
Male	26 (70.3)	6 (66.7)	13 (56.5)	8 (50.0)	4 (36.4)
Female	11 (29.7)	3 (33.3)	10 (43.5)	8 (50.0)	7 (63.6)
Age, y:mo					
M (*SD*)	8:7 (4:4)	9:1 (4:9)	9:9 (5:3)	9:8 (4:1)	7:10 (5:2)
Age of onset, y:mo					
M (*SD*)	4:5 (3:9)	2:11 (3:1)	6:1 (5:4)	4:9 (3:8)	5:0 (4:3)
Seizure Type[a], *n* (%)					
Focal onset					
With impairment of awareness	18 (48.6)	3 (33.3)	9 (39.1)	-	5 (45.5)
Without impairment of awareness	14 (37.8)	4 (44.4)	6 (26.1)	1 (6.3)	-
Evolving to convulsive	16 (43.2)	-	6 (26.1)	1 (6.3)	1 (9.1)
Additional information unknown	-	-	-	4 (25.0)	-
Generalised onset					
Motor- Tonic-clonic	14 (37.8)	8 (88.9)	11 (47.8)	9 (56.3)	4 (36.4)
Motor- Other	7 (18.9)	6 (66.7)	6 (26.1)	7 (43.8)	2 (18.2)
Non-motor (Absence)	17 (45.9)	8 (88.9)	8 (34.8)	9 (56.3)	4 (36.4)
Epilepsy Type, *n* (%)					
Focal	16 (43.2)	-	6 (26.1)	5 (31.3)	4 (36.4)

Generalised	19 (51.4)	3 (33.3)	8 (34.8)	10 (62.5)	6 (54.5)
Combined Focal & Generalised	2 (5.4)	6 (66.7)	9 (39.1)	1 (6.3)	1 (9.1)
Epilepsy Syndromes[b], *n* (%)					
Diagnosed syndrome	7 (18.9)	1 (11.1)	2 (8.7)	7 (43.7)	3 (37.3)
No syndrome	30 (81.1)	8 (88.9)	21 (91.3)	9 (56.3)	8 (72.7)
Aetiology, *n* (%)					
Genetic	3 (8.1)	4 (44.4)	1 (4.3)	1 (6.3)	-
Structural	2 (5.4)	-	2 (8.7)	1 (6.3)	2 (18.2)
Genetic/Structural	4 (10.8)	-	1 (4.3)	1 (6.3)	-
Infectious	1 (2.7)	-	-	1 (6.3)	-
Unknown	27 (73)	5 (55.6)	19 (82.6)	12 (75)	9 (81.8)
Seizure Frequency, *n* (%)					
Daily	7 (18.9)	1 (11.1)	4 (17.4)	-	3 (27.3)
Weekly	4 (10.8)	4 (44.4)	3 (13.0)	-	2 (18.2)
Monthly	5 (13.5)	1 (11.1)	3 (13.0)	2 (12.5)	1 (9.1)
Less than monthly	14 (37.8)	2 (22.2)	10 (43.5)	8 (50.0)	5 (45.5)
No Seizures for 2 years	7 (18.9)	-	3 (13.0)	3 (18.8)	-
Unknown	-	1 (11.1)	-	3 (18.8)	-
Antiepileptic medication, *n* (%)					
Monotherapy	23 (62.2)	4 (44.4)	13 (56.5)	14 (87.5)	9 (81.8)
Polytherapy	10 (27.0)	5 (55.6)	9 (39.1)	2 (12.5)	2 (18.2)
None	4 (10.8)	-	1 (4.3)	-	-
Comorbidities[c], *n* (%)					
ASD	6 (16.2)	4 (44.4)	3 (13.0)	3 (18.8)	2 (18.2)

Learning Difficulties	5 (13.5)	1 (11.1)	7 (30.4)	5 (31.3)	-
Developmental Delay	2 (5.4)	2 (22.2)	-	7 (43.8)	-
Cerebral Palsy	2 (5.4)	-	-	2 (12.5)	-
ADHD	1 (2.7)	1 (11.1)	1 (4.3)	3 (18.8)	3 (27.3)
None	25 (67.6)	4 (44.4)	15 (65.2)	5 (31.3)	8 (72.7)
Support at School, *n* (%)					
No	15 (40.5)	2 (22.2)	9 (39.1)	5 (31.3)	4 (36.4)
Yes	12 (32.4)	3 (33.3)	9 (39.1)	8 (50.0)	3 (27.3)
Attends Special School	7 (18.9)	3 (33.3)	2 (8.7)	1 (6.3)	1 (9.1)
N/A (e.g. too young)	3 (8.1)	1 (11.1)	3 (13.0)	1 (6.3)	3 (27.3)
Not Known	-	-	-	1 (6.3)	-

Note. Seziure type, epilepsy type and aetiology are classified according to the new ILAE classification of epilepsies (2017).
[a]Seizure type is not mutually exclusive as patients can experience multiple types of seizures.
[b]Epilepsy syndromes have been collapsed into one category to maintain anonymity of the participants.
[c]Comorbidities are not mutually exclusive as patients can have multiple diagnoses.

Interview Sample

Table 3.6

Demographic data of participant carers of CWE

	Area 1-ESN (*n* = 17)	Area 2-ESN (*n* = 6)	Area 3-ESN (*n* = 14)	Area 4-NoESN (*n* = 16)	Area 5-NoESN (*n* = 5)
Relationship to child, *n* (%)					
Mother	15 (88.2)	6 (100)	13 (92.9)	16 (100)	5 (100)
Father	2 (11.8)	-	1 (7.1)	-	-
Age, y:mo					
M (*SD*)	38:1 (8:0)	43:10 (7:3)	36:9 (6:9)	40:5 (8:2)	36:4 (4:0)
Ethnicity, *n* (%)					
White British	14 (82.4)	6 (100)	13 (92.9)	16 (100)	5 (100)
Asian British	3 (17.6)	-	1 (7.1)	-	-
Yrs of Post-16 Ed					
M (*SD*)	3.25 (2.96)	2.6 (1.82)	2.25 (2.14)	2.47 (2.26)	2.0 (1.73)

Table 3.7

Clinical features of CWE

	Area 1-ESN (*n* = 17)	Area 2-ESN (*n* = 6)	Area 3-ESN (*n* = 14)	Area 4-NoESN (*n* = 16)	Area 5-NoESN (*n* = 5)
Gender, *n* (%)					
Male	15 (88.2)	5 (83.3)	6 (42.9)	9 (56.3)	3 (60)
Female	2 (11.8)	1 (16.7)	8 (57.1)	7 (43.8)	2 (40)
Age, y:mo *M* (*SD*)	8:9 (4:10)	9:4 (5:0)	10:0 (5:2)	9:7 (3:11)	6:5 (5:4)
Age of onset, y:mo *M* (*SD*)	5:6 (4:7)	3:2 (2:3)	5:2 (5:2)	4:8 (3:9)	3:9 (3:8)
Seizure Type, *n* (%)					
Focal onset					
With impairment of awareness	10 (58.8)	2 (33.3)	9 (64.3)	-	2 (40)
Without impairment of awareness	8 (47.1)	1 (16.7)	4 (28.6)	1 (6.3)	-
Evolving to convulsive	9 (52.9)	-	3 (21.4)	1 (6.3)	1 (20)
Additional information unknown	-	-	-	4 (25)	-
Generalised onset					
Motor- Tonic-clonic	4 (23.5)	5 (83.3)	6 (42.9)	10 (62.5)	3 (60)
Motor- Other	3 (17.6)	2 (33.3)	4 (28.6)	7 (43.8)	1 (20)
Non-motor (Absence)	8 (47.1)	5 (83.3)	6 (42.9)	9 (56.3)	2 (40)

Epilepsy Type, *n* (%)					
Focal	9 (52.9)	-	4 (28.6)	5 (31.3)	1 (20)
Generalised	7 (41.2)	3 (50)	4 (28.6)	10 (62.5)	3 (60)
Combined Focal & Generalised	1 (5.9)	3 (50)	6 (42.9)	1 (6.3)	1 (20)
Epilepsy Syndromes, *n* (%)					
Diagnosed syndrome	5 (29.4)	1 (16.7)	1 (7.1)	7 (43.7)	1 (20)
No syndrome	12 (70.6)	5 (83.3)	13 (92.9)	9 (56.3)	4 (80)
Aetiology, *n* (%)					
Genetic	1 (5.9)	2 (33.3)	-	1 (6.3)	1 (20)
Structural	-	-	1 (7.1)	1 (6.3)	-
Genetic/Structural	2 (11.8)	-	1 (7.1)	1 (6.3)	-
Infectious	1 (5.9)	-	-	1 (6.3)	-
Unknown	13 (76.5)	4 (66.7)	12 (85.7)	12 (75)	4 (80)
Seizure Frequency, *n* (%)					
Daily	4 (23.5)	1 (16.7)	2 (14.3)	1 (6.3)	1 (20)
Weekly	2 (11.8)	1 (16.7)	2 (14.3)	-	2 (40)
Monthly	1 (5.9)	-	3 (21.4)	2 (12.5)	-
Less than monthly	8 (47.1)	3 (50)	5 (35.7)	8 (50)	2 (40)
No Seizures for 2 years	2 (11.8)	-	2 (14.3)	3 (18.8)	-
Unknown	-	1 (16.7)	-	2 (12.5)	-
Antiepileptic medication, *n* (%)					
Monotherapy	12 (70.6)	3 (50)	8 (57.1)	14 (87.5)	3 (60)
Polytherapy	5 (29.4)	3 (50)	5 (35.7)	2 (12.5)	2 (40)
None	-	-	1 (7.1)	-	-

Comorbidities, *n* (%)					
ASD	4 (23.5)	4 (66.7)	2 (14.3)	3 (18.8)	2 (40)
Learning Difficulties	1 (5.9)	2 (33.3)	7 (50)	6 (37.5)	-
Developmental Delay	2 (11.8)	-	1 (7.1)	6 (37.5)	-
Cerebral Palsy	-	-	-	2 (12.5)	-
ADHD	-	1 (16.7)	-	3 (18.8)	2 (40)
None	10 (58.8)	2 (33.3)	6 (42.9)	5 (31.3)	3 (60)
Support at School, *n* (%)					
No	7 (41.2)	1 (16.7)	5 (35.7)	5 (31.3)	1 (20)
Yes	7 (41.2)	2 (33.3)	5 (35.7)	9 (56.3)	2 (40)
Attends Special School	2 (11.8)	2 (33.3)	2 (14.3)	1 (6.3)	-
N/A (e.g. too young)	1 (5.9)	1 (16.7)	1 (7.1)	-	2 (40)
Not Known	-	-	1 (7.1)	1 (6.3)	-

Chapter Four: Carer Evaluations of Paediatric Epilepsy Services- A Questionnaire Study

4.1 Introduction

The effects of epilepsy on both the child with epilepsy (CWE) and the family have been outlined in chapter one and two of this thesis. In this chapter the first study of this thesis will be presented. The aim of this study is to evaluate carer's experiences of paediatric epilepsy services specifically on measures of satisfaction, ongoing carer/patient needs and accessibility. This will be done by comparing service areas with and without paediatric epilepsy specialist nurses (ESNs) by way of a questionnaire. For clarity, this study will be referred to in this chapter and throughout the thesis as the "questionnaire study". It is referred to as "Study One" in the published paper (Beesley et al., 2021).

On evaluation of the literature presented in chapter two, it is clear that ESNs provide a considerable contribution to adult epilepsy services (Campbell et al., 2019; Prevos-Morgant et al., 2019). However, there is a lack of research on paediatric epilepsy services; this study was designed to address the gap. The majority of studies evaluating services in adult populations use self-report measures of satisfaction (Ridsdale et al., 2000) and ongoing patient needs (Long et al., 2005) therefore, measures were selected that would also address these needs in CWE and their families. On review of the ESN literature, accessibility was found to be a central component to the work that is done by ESNs in the UK context (Higgins et al., 2019; Kirkpatrick et al., 2014; Williams et al., 2018). The addition of a question that would measure this is outlined below.

4.2 Measures

Historically, there have been very few measures to assess parent/carer needs and experience of epilepsy. Until the late 1990s there were no measures that specifically addressed the needs of CWE and their parents, which is surprising given there were approximately 150,000 young people evaluated for new onset seizures annually at the time in the US (Hauser, 1994). For this reason Austin et al. (1998) developed and validated the first self-report measure, the Parent Report of Psychosocial Care Scale (PRPCS), which was designed to measure both satisfaction with care received, as well as degree of unmet needs, in carers of children with epilepsy. There were other measures used prior to this and more have been developed since. Ridsdale et al. (1999) measured the effect of ESNs on patient knowledge in people with epilepsy (PWE) over the age of 16 yrs by way of a questionnaire developed by Jarvie et al. (1993). It consisted of 55 items; 34 that measured general medical epilepsy knowledge and 21 that measured social knowledge that was epilepsy specific. However, this measured knowledge only and did not examine unmet needs or patient satisfaction. Chinthapalli et al. (2008) conducted an audit of epilepsy clinic services including use of a questionnaire of patient satisfaction. The questionnaires were posted to parents to complete anonymously. Although this approach examined some aspects of patient satisfaction, the questions were somewhat limited in focus given they were in direct response to the NICE epilepsy audit. They concentrated exclusively on staff courtesy, communication and clinic visits. Other scales have been developed more recently. In 2016, Pfäfflin and colleagues assessed satisfaction with epilepsy care in PWE in Germany. The primary outcome measures were patient satisfaction with information and support, specifically focused on the efficacy of adult ESNs. Higgins et al. (2018) conducted a self-report questionnaire study with PWE

comparing areas with and without an ESN in Ireland. Again this was an adult population as opposed to parent/carers of CWE, however, determining differences in services with and without ESN provision was the key focus of the study. They used a measure of satisfaction consisting of 43 items that included questions on information provided about epilepsy, the medical and social aspects of epilepsy, and understanding of safety procedures. Similarly, Hague et al. (2020) conducted a questionnaire study comparing areas with and without an ESN. They used an abbreviated version of a new measure developed by the National Centre for Epilepsy and the Norwegian Epilepsy Association. The full version contains 56 items (see Henning et al., 2019) however, Hague and colleagues only used a few of these questions for their study. In addition to background information regarding their epilepsy and information they had received, participants were asked about ESN follow-up.

When considering measures for this study, the scale that seemed most appropriate for this study was the PRPCS (Austin et al., 1998). Questionnaires developed after 2016 could not be considered for this study as data collection had been completed at this point. However, informed by Williamson and Hoggart (2005), assessing the comprehensibility and power to detect differences of different response scales, the original 3-point response scale was replaced with a 10cm visual analogue scale (VAS) to increase power to detect differences.

The PRPCS (Austin et al., 1998) has two sub-scales; “Satisfaction with Care Received” and “Remaining Needs for Information and Support”. For the purposes of this study, an additional question regarding accessibility of service was added at the end of the Satisfaction with Care Received subscale, although analysed as a separate dependent variable. In the UK context of NHS services, and in discussion with our clinical colleagues, we reasoned that accessibility to ESNs relative to paediatricians

could be a key variable to examine. This was confirmed in later research by Williams et al., (2018), based a questionnaire study of over 2300 parents/carers of young people with epilepsy, which reported that the strongest influencing factor predicting satisfaction with service was “ease of access”. They reported that parents would experience decreased satisfaction with services if they had difficulty contacting services, if they felt staff “did not make it easy for them” to attend clinics, and if they believed they were not seen enough. Conversely, parents who found it easy to contact services reported high levels of satisfaction. Due to the focus on ESNs, it is important that this study further investigates the established link between satisfaction with services and accessibility of service to establish whether the presence of an ESN has a positive effect.

It was predicted that level of unmet need would not differ between groups, as childhood epilepsy presents different challenges as development progresses (Shore et al., 2009), therefore requiring ongoing interaction with services. It was predicted that levels of satisfaction with services would be greater in areas with a paediatric ESN. Additionally, it was predicted that scores of accessibility would be higher in areas with ESNs.

4.3 Method

4.3.1 Participants

Participants were the parents or carers of CWE identified from the caseload of consultant paediatricians from five NHS trusts in the North West of England. These five areas are fully described in chapter 3. Three of these areas had ESNs. An overview of their training and experience is provided in Table 3.1, chapter 3. Explanations of the ethics procedure, sample identification, recruitment process, response rates, participant demographics, and clinical information of the CWE for this

study were also given in the previous chapter (see Table 3.2, Figure 3.1, Table 3.4 and Table 3.5 of Chapter 3). In order to detect a medium effect size at 80% power, a sample size of 64 participants in each of the ESN and non-ESN groups was aimed for. This did not factor in any measure of intra-cluster correlation coefficients arising from the use of different areas (see Killip et al., 2004), as we had no basis to estimate these. Ninety-six parents/carers provided questionnaire data out a total of 554 that were eligible (see Figure 3.1, Chapter 3). While the target number for ESN area participants was met (n = 69), that for non-ESN areas was not met (n = 27).

4.3.2 Procedure

Each time a research nurse advised the research team of participant consent for the study, a hard copy of the questionnaire (see Appendix 1) was posted directly to the participants homes. The letterhead for the cover letter (see Appendix 2) was changed to include the appropriate NHS trust logo as per the agreement with each trust. Participants were asked to complete the questionnaire by hand and return via a pre-paid envelope enclosed in the pack. They were advised that there were a few questions about themselves and their child (demographic information) and then 23 questions that relate their experience with the doctors and nurses within the epilepsy service and the support they have received for their child's seizure condition. There were written instructions to respond to each of the questions with the response that best describes how they feel. For the first section that measures Satisfaction with Care Received, participants were instructed to mark on the line between the words “hardly” and “fully”. For the section that measures Remaining Needs for Information and Support they were instructed to mark on the line between the words “not at all” and “a great deal”. The cover letter had contact details for the research team and they invited to contact them if they had any questions. Participants were initially informed that the

study concerned all aspects of service provision, and were only debriefed that the study had a focus on ESN provision once their participation was over. At the conclusion of the study a debrief letter was sent directly to participants homes via post.

4.3.3 Design

This study employed a quasi-experimental non-equivalent groups post-test only design. The factors were the service areas and the classification of those areas as an ESN factor (i.e., ESN and no-ESN). The dependent variables were the scores on the Satisfaction with Care Received sub-scale of the Parent Report of Psychosocial Care Scale (PRPCS) (Austin et al., 1998), the scores on the Remaining Needs for Information and Support sub-scale of the PRPCS, and the score received concerning accessibility of clinicians in between regular appointments.

4.3.4 Measures

An adapted version of the PRPCS was utilised (Austin et al., 1998), whereby the original categorical response options were replaced with a 10 cm visual-analogue scale (VAS) (Williamson & Hoggart, 2004). The Satisfaction with Care Received subscale contained eight questions, concerning whether doctors/nurses provided sufficient information on seizure handling, AEDs, school liaison, emergency procedures, as well as addressing concerns. The sub-scale on Remaining Needs for Information and Support comprised of 14 questions, covering needs for information on handling the epilepsy, concerns for the future, and mental health support. As explained above, a further question on accessibility of doctors/nurses between regular appointments was added, with responses being made on the 10 cm VAS scale (see appendix 1 for full questionnaire), which was analysed as a separate DV.

4.3.5 Data analysis

All responses were scored by manual measurement by a researcher blind to participant, area and the research hypotheses, with a randomly selected 10 checked for accuracy, with 100% agreement obtained (+/−1 mm). The total score for the Satisfaction with Care Received sub-scale was the mean score of the 8 questions. There were 10 participants with missing data on the question concerning service in relation to schools, as this only applied to school-aged children. In these cases, the total Satisfaction with Care Received score was the mean of the remaining seven questions. The total Remaining Needs for Information and Support score was the mean score for the 14 questions comprising this subscale. The question concerning accessibility of service in between regular appointments was analysed as a separate DV.

In order to address the question of whether either the independent variable of Area or presence of ESN was related to scores on the PRPCS subscales, or accessibility between appointments, our original analysis plan was to adopt a general linear modelling (GLM) forward-fitting approach, whereby Area would be entered as a factor, and this model compared with the intercept using the Bayes Information Criterion (BIC). Then, an intercept plus ESN model would be run, and the BIC compared to the model containing intercept and Area. If Area or presence of ESN had no effect on scores, then the intercept model would have the lowest BIC score, whereas if either Area or the ESN factor had the lowest BIC score, then whichever provided the model of best fit would be accepted. Such a comparison of models is required as it is possible that areas reliably differ from each other for reasons other than the presence of an ESN. However, due to the negative skew in the data, owing to the frequency of ceiling scores, the residuals of the models of all three dependent

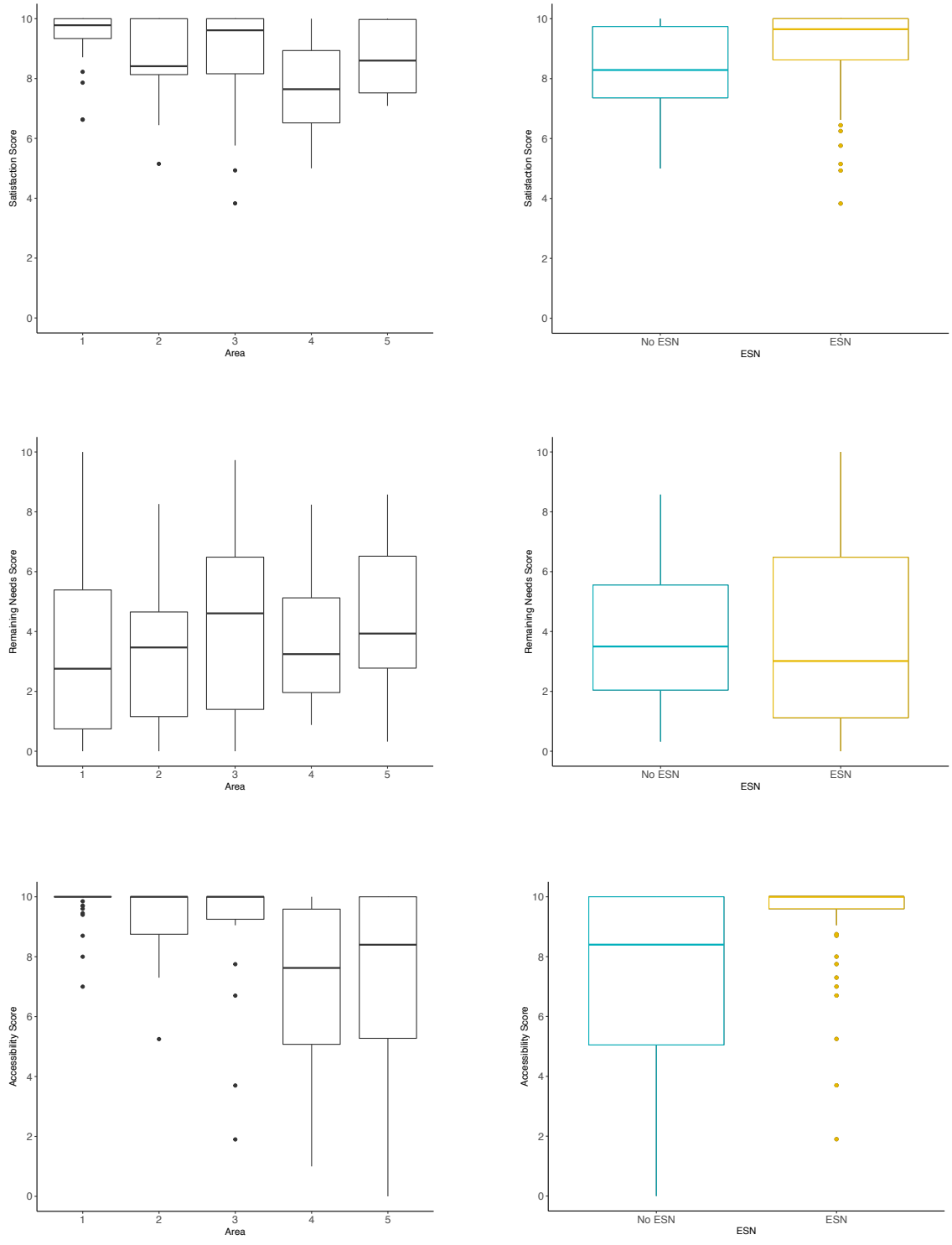
variables were not normally distributed, thereby violating the assumptions underlying GLMs. Consequently, the data were transformed to take a binary form, with scores either being below the overall median, or equal to and above the median score. The models were then run using logistic regression, following the forward-fitting approach outlined above. Using the categorical data, a chi squared test of independence was also conducted on each individual question to assess whether there were any significant differences in areas with or without an ESN. These latter analyses were exploratory, to see whether particular items showed greater differences between ESN and non-ESN areas.

4.4 Results

The reliability of the adapted PRPCS scale was good (Chronbach's alpha for the Satisfaction with Care Received subscale was 0.86 and for Remaining Needs was 0.94). Figure 4.1 shows the medians and interquartile ranges of the Satisfaction with Care Received scale, Remaining Needs scale and the accessibility scores by area and by ESN factor. For the Satisfaction with Care Received scores, the ESN factor was the model of best fit, although there were only 1.8 BIC points between this model and the intercept only model, which was the next best model. For accessibility score, the model containing ESN as a factor was considerably better than the intercept only model (8.2 BIC points), which was the next best-fitting model. Remaining Needs scores were similar across areas, and neither Area nor the ESN factor added any explanatory power to the intercept only model. Table 4.1 displays the best-fitting models for satisfaction with service and accessibility scores.

Figure 4.1

Medians and interquartile ranges for satisfaction with service score, remaining needs score and accessibility score, as a function of Area and the ESN factor.



Note. Areas 1-3 are ESN areas, and 4-5 are Non-ESN areas.

Table 4.1

Parameter estimates for best-fit logit model of satisfaction score and accessibility score, with ESN as a predictor

Measure	Parameter	Estimate (β)	*SE*	95% CI	*p*	*OR*
Satisfaction Score	Intercept	-.88	.42	-1.69-(-.04)	.04	NA
	ESN	1.19	.49	.23-2.14	.015	3.28[a]
Accessibility Score	Intercept	-.87	.42	-1.69-(-.04)	.04	NA
	ESN	1.69	.5	.72-2.66	.001	5.43[b]

Note. The No-ESN group is used as the reference category in all analyses. All scores were recoded as binary variables (< median score, ≥ median score). [a]Small effect size. [b]Medium effect size (see Chen et al., 2010).

A chi-square test was conducted on each individual question of both the satisfaction with service scales (see Figure 4.3) and Remaining Needs for Information (see Figure 4.4). These analyses were exploratory, to address whether certain questions were driving differences between ESN and non-ESN areas, relative to other questions, Results were not significant for the majority of the questions, with the exception of three questions, two of which were from the satisfaction with service scale.

For question 3 of the satisfaction with service scale, which asked if the doctors/nurses described any problems from the medicine that would need to be reported immediately, the ESN area scored significantly higher X^2 (1, N = 94) = 4.41, p = .04 p < .05. On question 5 of the satisfaction with service scale, which asked if the doctors/nurses gave an opportunity to ask questions about the seizures, the ESN area scored significantly higher X^2 (1, N = 94) = 4.52, p = .03 p < .05

The second set of questions, which addressed Remaining Needs, were subject to the same analyses and only one question showed a significant difference (see Figure 4). Question 3, which asked if carers felt they needed information about the causes of seizures, scored significantly higher in areas without an ESN X^2 (1, N = 95) = 6.62, p = .01 p < .01.

Figure 4.2

Medians and interquartile ranges for individual questions within the satisfaction with service measure.

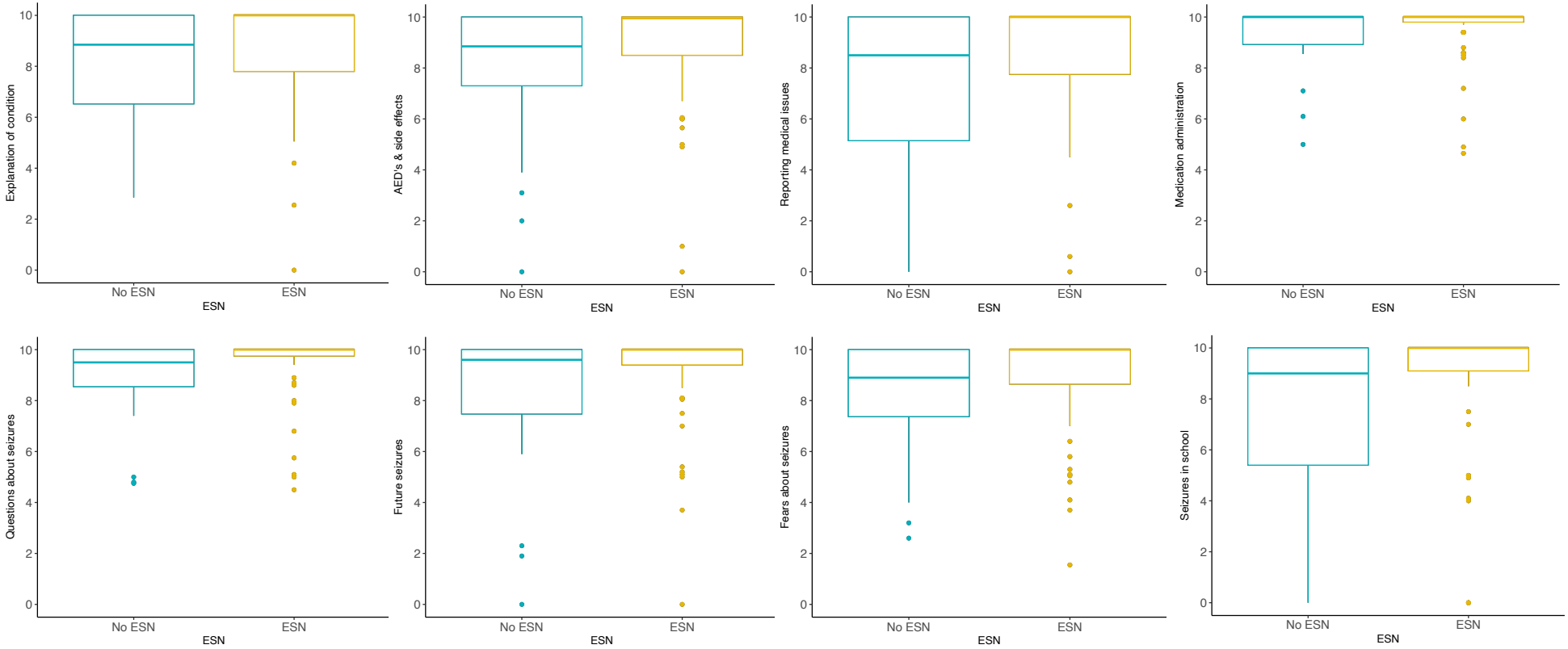
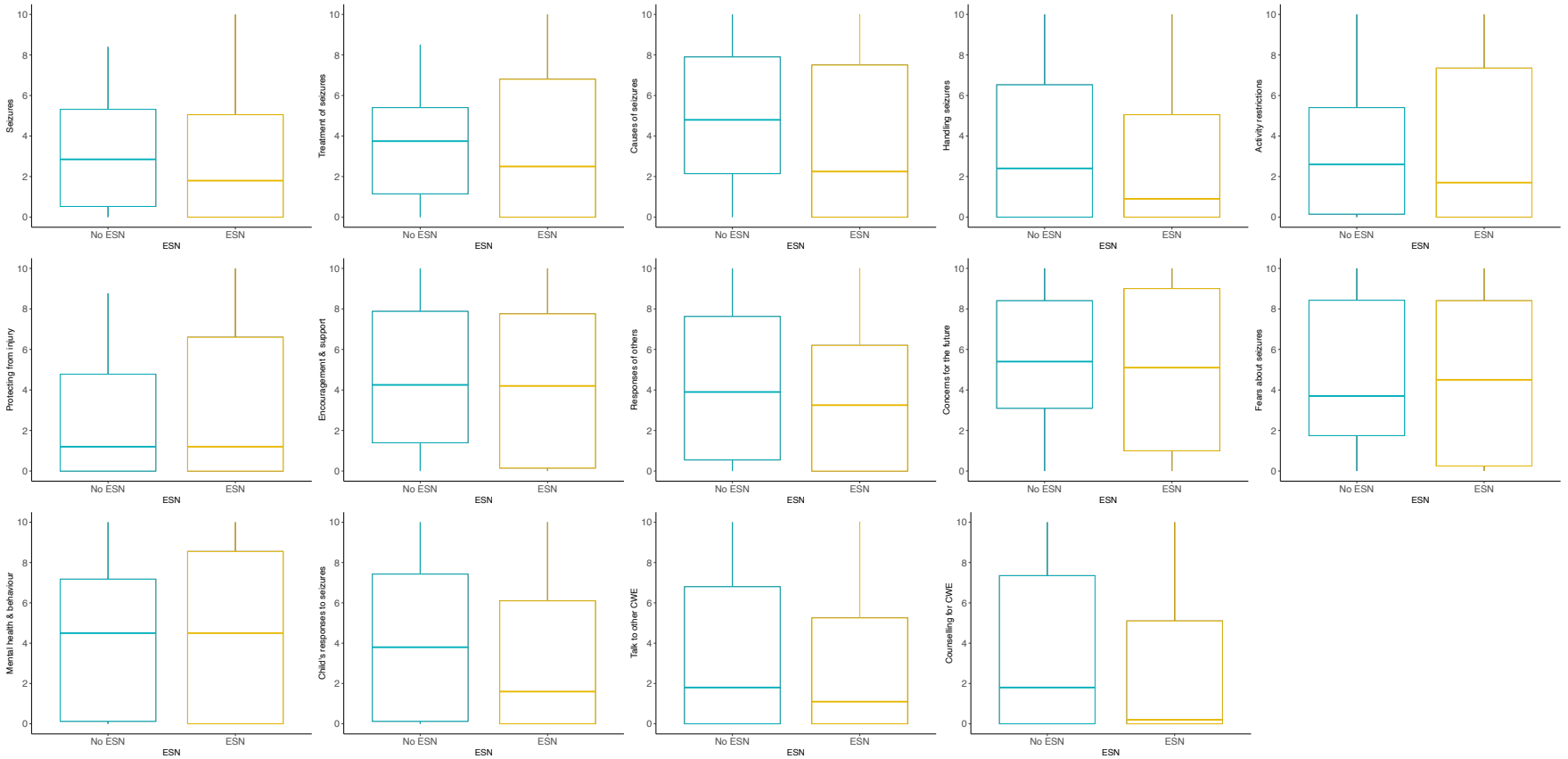


Figure 4.3

Medians and interquartile ranges for individual questions within the remaining needs measure.



4.5 Discussion

The main objective of this study was to evaluate carers' experiences of paediatric epilepsy services, specifically on measures of service satisfaction, ongoing carer/patient needs, and accessibility of service. Overall, satisfaction with service levels were high across all areas, which is consistent with earlier findings (Higgins et al., 2018; Williams et al., 2018). However, carers from areas with ESNs were over 3 times more likely to endorse scores at the median or above than were carers from non-ESN areas. In terms of remaining needs for information, scores showed high variability across all areas and were unaffected by the presence of an ESN. On the measure of accessibility, ESN areas scored significantly higher, with over 5 times more likelihood of endorsing scores above the median.

4.5.1 Satisfaction with services

Generally, patient satisfaction is associated with better engagement with treatment, appropriate care-seeking, and understanding and retention of medical information (De Silva & Valentine, 2000). Consistent with previous research (Helde et al., 2005; Higgins et al., 2018), the results indicate that epilepsy services with paediatric ESNs generate higher levels of carer satisfaction than areas without. The PRPCS scale used to assess service satisfaction (Austin et al., 1998) examined a variety of areas that may have contributed to the overall levels of service satisfaction. Participants were asked how well they felt the seizure condition was explained and if they had the opportunity to ask questions about seizures. The provision of an ESN can provide a better opportunity for the dissemination of complex medical information in an accessible way (Ek Hauge et al., 2020). Although doctors and consultants can explain the complexities of seizures to patients and their families, there is often not enough time in an appointment to discuss patient concerns fully (Cook et al, 2023;

Hopkins & Irvine, 2012). Having an ESN as part of the service may help parents/carers feel they can direct questions to them. This may be helpful if they do not fully understand what a consultant is saying and there is not enough time for them to feel they have received a clear explanation. Having an ESN in a service provides greater opportunities within and outside of clinic appointments for parents to ask questions and raise issues. Being experts (Prevos-Morgant et al., 2019), ESNs are thereby well-placed to provide high quality information to parents/carers outside of clinic appointments. These claims are supported by the exploratory analysis in this study, whereby the ESN area scored significantly higher on the specific question relating to being given opportunities to ask questions about seizures. It is possible that further questions can arise after a clinic appointments, once the parent/carer has had time to digest the information given to them. Having access to an ESN, as part of the epilepsy team, may help towards parents/carers feeling they can contact someone outside of clinic appointments for these types of queries. For this reason, the accessibility scores may have contributed to the satisfaction scores, but much higher participant numbers would be needed to test this statistically. It is possible patients could feel they are disturbing or unnecessarily troubling a consultant, but as nurses can be perceived as more approachable (Collins, 2005), it is more likely parents/carers would feel comfortable contacting them. This may account for the differences found in the exploratory analysis and contribute to overall satisfaction with the service.

Another key area for patient/carer satisfaction is information provision and understanding in relation to medication. Again, these were areas that contributed to the overall service satisfaction levels being higher in areas with an ESN. ESNs are generally highly qualified and experienced medical professionals who carry out many of the same responsibilities as a consultant (Prevos-Morgant et al., 2019). They are

able to carry out drug reviews, deal with queries relating to anti-epileptic medication, and some ESNs are certified to prescribe certain medications. Studies such as Ek Hauge et al. (2020), report that adult patients with epilepsy who receive ESN support are better informed about epilepsy related topics. They suggest this may be due to the additional time ESNs allocate to individualised patient education compared to the time afforded to and by doctors or consultants. This may be similar for parents/carers who are able to interact with paediatric ESNs. Some queries may be general such as, medication related changes in behaviour and non-urgent side effects, e.g. lethargy. However, other issues around medication may be time sensitive and require a quick response, e.g. what to do if a CWE has vomited after taking medication, or advice on whether they need to attend hospital due to particular circumstances. Having the opportunity to ask questions about issues with medication, either in advance of events or at the time, and receiving a response, is an invaluable resource for parents/carers. ESNs have a wealth of knowledge and experience on a very practical level as they work closely with many families. It is likely that having access to timely medical support at this level, in addition to a consultant, contributes to the high service satisfaction scores. Additionally, in the exploratory analysis, the specific question regarding explanation of issues with medication that would need to be reported immediately, the ESN area scored significantly higher, thus supporting these claims.

Participants were also asked whether doctors/nurses explained what to do in the event of future seizures, whether their concerns/fears were addressed and if they knew how to handle seizures at school. ESNs are able to dedicate more time to social and emotional needs in comparison to medical doctors (Ek Hauge et al., 2020) and this leads to a more holistic level of care (Locatelli et al., 2021). ESNs can provide consistent support to patient's families, as such they have the unique opportunity to

develop meaningful relationships with them over time. An ESN service provides for an understanding of the family's complex needs and the provision of advice and support the parents/carers can trust. ESNs can also assist with epilepsy training and education for other professionals involved in the CWE's life. This can be a valuable resource, especially if parents/carers do not feel confident in their own ability to deal with events and may feel out of their depth and unqualified to explain and train others. Again, these may be contributing factors for those in areas with ESNs experiencing an improved sense of satisfaction with epilepsy services.

Overall, as the accessibility score (discussed below) showed a significant difference between service type, this could have fed in to the differences in the satisfaction, especially the difference found in which side-effects of medication required immediate attention, and how to manage seizures.

4.5.2 Ongoing/remaining needs for information

The results of this study did not yield any differences in areas with or without ESNs in terms of remaining needs for information. Scores showed high variability across all areas and were unaffected by presence of an ESN. These findings are consistent with the predications made for this study. It was expected there would be no differences in the needs for information of parents/carers as epilepsy presents different challenges throughout childhood as development progresses (Shore et al., 2009). Epilepsy is not a static condition and as such, needs change as the child develops. There would be an ongoing need for information relevant to their current experience of the condition, regardless of service type. There would therefore, be a continual need for interaction with services throughout the child's life. These findings are supported by previous studies where no differences were found in patient knowledge of epilepsy in areas with and without an ESN (Ridsdale et al., 2000;

Warren et al., 1999). However, the results of the exploratory analysis indicated that parents/carers of CWE in areas without an ESN felt they needed significantly more information about the causes of seizures than those in areas with an ESN. More research in this area may be needed to determine any differences in the initial discussions about the causes of the condition between service type.

4.5.3 Accessibility of services

Participants were asked about ease of access to doctors/nurses if they had a question between regular clinic appointments, as accessibility is central to the work of ESNs (Kirkpatrick et al., 2014; Williams et al., 2018). Participants were asked specifically whether, if they had a question outside of clinic, they could contact doctors/nurses to get answers. Areas with an ESN scored significantly higher in this measure of accessibility.

Typically, patients are seen by clinicians at regular intervals. These intervals can range between 3-, 6- and 12-months depending on seizure severity, effectiveness of medication, and generally how well-controlled the seizures are. An important contributing factor to this result concerns accessibility of service when issues arise outside of regular clinic appointments. There are a number of factors that contribute to perceptions of accessibility. ESNs can offer more time to patients than consultants or GPs (Cook et al, 2023; Hopkins & Irvine, 2012). As such, they are more likely to be available to speak to and answer questions between regular appointments. Ease of access to service is also an important factor within accessibility (Williams et al, 2018) and highlights both the importance of medical and non-medical aspects of a service and the significance of additional communication with services outside of clinic appointments. Having a direct email address or a phone number they can call or text, and knowing there will be a response from a member of the team, can help service

users feel more supported by the service and ultimately more positive about accessing additional support. In areas with an ESN, typically, the ESN will give parents/carers their contact details which can include phone, text and email contact. This may contribute to parents/carers rating the ESN model of service higher in accessibility. More research is needed in this area to understand what specifically contributes to higher ratings of accessibility. A mixed-methods approach would allow for replication of the questionnaire study's results and give participants an opportunity to explain which aspects of a service they perceive as being more accessible.

4.6 Study Limitations

It is probable that this study underestimates the difference between ESN and non-ESN areas in terms of satisfaction scores, due to the difficulty of recruiting participants from non-ESN areas, an issue that also occurred in a recent national audit of paediatric epilepsy services (Williams et al., 2018). A higher rate of recruitment had been intended for this study, but it was difficult to recruit areas without an ESN as these areas seemed to have less resource and capacity to support recruitment. Areas with larger caseloads, fewer staff or stretched budgets would be less likely to engage with research if they were already struggling to manage duties amongst the team. However, due to the positive effects of the Epilepsy12 audit (NICE, 2012), more trusts have started training ESNs. Therefore, to our knowledge, at the time of data collection, the only no-ESN areas that were a commutable distance from Lancaster University were recruited to the study. However, it would be beneficial for future research if higher recruitment rates, especially in no-ESN areas, were achieved.

Studies that have investigated response rates of health related questionnaires suggest that those with strong opinions about their care experiences are more likely to complete and return questionnaires when invited to engage in research, especially

those with positive views (Mazer et al, 2002). Efforts were made to reduce response bias, with all eligible participants receiving questionnaires in the same way, with the same follow up procedures. However, as those with less positive experiences could be less likely to have participate, our findings may overestimate satisfaction with services, especially in non-ESN areas where there was lower participation.

One suggestion for future research would be to focus on longitudinal change in the experiences of parents/carers in services that have transitioned from non-ESN to ESN provision. Participants in areas without a nurse have never experienced ESN provision and are therefore only able to comment on their experience of an service without an ESN. It is difficult to compare certain aspects of a paediatric epilepsy service in this way. Investigating the views of service users that have experienced both models of the service may be yield invaluable information about aspects of the service that are most valuable to patients and families of CWE.

4.7 Conclusions

Despite the limitations outlined, this study (Beesley et al., 2021) is the first to compare ESN and non-ESN services directly within the paediatric field. Results are consistent to those in adult services (Helde et al., 2005; Higgins et al., 2018), favouring services with an ESN.

There are opportunities for future research to investigate the differences in accessibility ratings as this may be feeding into the differences found in satisfaction scores. This would bring opportunities for greater learning as any accessibility research conducted could also focus on the specific events that parents/carers contact services about and which they feel would need to be responded to. With regards to replication of this study, far greater participant numbers would be needed to then test what is feeding into the difference in satisfaction scores in the different items, to

statistically test whether accessibility score is explaining variation in satisfaction scores.

Consistent with the findings in this study, Williams and colleagues (2018) found that the strongest predictor of carer satisfaction with service was accessibility. But, as these authors state, in order to understand this relationship further, analysis of qualitative in-depth interview data is desirable. The interview study outlined in the subsequent chapter will address this gap.

Chapter Five: Carer Perceptions of Paediatric Epilepsy Services- A Thematic Analysis

5.1 Introduction

In this chapter, the methodology of the second study of the thesis will be presented, with the analysis and results presented in Chapter Six. The present study builds on the questionnaire study in the previous chapter by examining in-depth interviews of carers of CWE in areas with and without paediatric ESN provision, with respect to their experiences of epilepsy services throughout their child's epilepsy trajectory. The goal, using Thematic Analysis (Braun & Clarke, 2006), is to examine the experiences of carers in having their support needs met by ESN and non-ESN services. For clarity, this study will be referred to in this chapter and throughout the thesis as the "interview study". The study has previously been published in Seizure (Beesley et al, 2022).

Qualitative methods, specifically Thematic Analysis, has been used in research on the experience and support needs of carers of CWE, as reviewed in chapter 2, section 2.7. However, no studies to date specifically focus on a comparison of carer experiences of services with and without ESNs. As the aim of this study is to evaluate carer experience by comparing these service models, it was felt an interview study would be the best way to explore the individual experiences of these participants. Focus groups and other methods were considered however, we wanted a dataset rich in individual experience so we could explore specific issues that have led to specific attitudes or beliefs rather than a group consensus to broader issues. Given the length of the project, we had enough time and resources to conduct the study in this way. We were also mindful of the need to shield participants from the fact we were comparing services until they were debriefed. The interviews were conducted in the same way

using the same interview schedule for both types of service (see Figure 5.1). Interviews are widely used in healthcare research (Brobeck et al, 2011; Galvin et al, 2013; Molin et al, 2016; Schwarz et al, 2022) so overall it was felt this was the most appropriate method to conduct this study. As such, qualitative methods will be outlined with a particular focus on Thematic Analysis (Braun & Clarke, 2006) and a rationale provided for its adoption as the analytic method for this study and for the epistemological position adopted. Finally, the methodology of the interview study will be presented.

5.2 Methodology rationale

Qualitative research offers a methodology through which researchers can investigate the experiences of individuals by enabling them to share their own personal perspectives (Flick, 1998). Qualitative methods have been used in psychological research for many years, however, renewed interest began from the 1970s with development of approaches such as Grounded Theory (Glaser & Strauss, 1967), Conversation Analysis (Sacks et al, 1974), phenomenology (Spiegelberg, 1981), and Discourse Analysis (Gee, 1999). Some of the most widely used techniques have been developed and refined over the years since, culminating in the approaches that are used today. Arguably the most commonly used qualitative method within psychology and specifically within the epilepsy research is Thematic Analysis (TA) (Braun & Clarke, 2006). When reviewing other research in this area the majority of studies adopted an TA approach (Harden et al, 2016; Rawlings et al, 2017). Due to the advantages of this analysis (outlined below), this was the chosen method of analysis for this study. The analytical process will be outlined in the next section.

5.2.1 Thematic Analysis

Thematic analysis is a qualitative research method that involves identifying and analysing themes from textual data. These are typically the transcripts of individual interviews or focus group discussion, though any textual data may be subject to analysis. In their foundational paper, Braun and Clarke (2006) identified six key phases to this method of analysis (see also Clarke & Braun, 2013; 2017 for updated accounts of the method). Firstly, they suggest the analyst familiarises themselves with the data through a process of transcribing, reading and re-reading the data. The time-consuming nature of this task is highlighted, however, the authors strongly advise that it is done so that the researcher is familiar with the data and can start making initial notes and ideas for coding schemes as patterns appear. Secondly, initial codes are generated. Blocks of text are coded according to their semantic (explicit) and latent (implicit) content and meanings. This is done systematically across the whole dataset. The next phase is to generate themes. This is done by identifying patterns across the codes and gathering the relevant data. The themes are then reviewed to ensure internal coherence, i.e., the coded data located within a theme has a coherence to it, and external distinctiveness, i.e., the codes and data located under separate themes reflect different experiences or understandings of the topic. The themes are reviewed to ensure that they reflect content of the entire data set, before being defined and named. The final stage of the analysis is producing a report that provides a coherent and concise interpretative narrative of the data, both within and across the themes. This includes providing extracts from the data to illustrate examples of specific codes and demonstrate the themes being presented. There are a number of strengths to thematic analysis; as a method, it is relatively easy to learn and engage with, it is useful in summarising the key areas of large data sets, it allows for

social and psychological interpretation of data and it can generate unexpected insights. Given these advantages and that it is the dominant choice for qualitative analysis in the field, thematic analysis was the chosen method for analysing the interview data in this study. One other reason for the popularity of Thematic Analysis is that it not wedded to any particular epistemological position, it is inherently neither realist nor constructionist, but Braun and Clarke (2006) are clear that researchers should be clear about the epistemological (and other) assumptions that they are making in relation to their data.

5.2.2 Epistemology

The position adopted in the following analysis is driven by two primary concerns. First, the overall aim of this project was to understand how patients and carers experience the reality of having a child with epilepsy and the healthcare support they receive. Secondly, when participants were recruited to take part in the interviews, they were informed that the research was concerned with their experiences, their thoughts and feelings. Consequently, in order to honour these empirical and ethical commitments, this research and the following analysis will adopt a critical realist position (Maxwell, 2012). That is it will adopt a realist ontological position, which recognises the material realities of childhood epilepsy and its consequences, and a constructivist epistemological position wherein the interviewee's accounts of their thoughts, feelings and experiences are recognised as their subjective accounts originating from their unique perspective.

The aim of this study was to examine the experiences of carers in having their support needs met by ESN and non-ESN services. This was done by interviewing parents/carers of CWE from areas with and without an ESN.

5.3 Method

5.3.1 Participants

Participants were the parents or carers of CWE identified from the caseload of consultant paediatricians from five NHS trusts in the North West of England. These five areas are fully described in chapter three. Three of these areas had ESNs. An overview of their training and experience is provided in Table 3.1, chapter three. Explanations of the ethics procedure, sample identification, recruitment process, response rates, participant demographics, and clinical information of the CWE for this study were also given in chapter three (see Table 3.3, Figure 3.2, Figure 3.3, Table 3.6 and Table 3.7 of chapter 3). To summarise, there were 58 participants; 37 from three service areas with ESNs (Areas 1, 2 and 3), and 21 from two areas without ESNs (Areas 4 and 5). Participants were informed that the study aimed to examine their experiences of all aspects of service provision. The focus on comparison between ESN and non-ESN services was not revealed until the debrief stage.

5.3.2 Procedure

Interviews were conducted by the research team for this study. Interviews typically took place in the carer's home, lasted approximately 1 hour and were audio-recorded. The interviews were semi-structured as this allows for the participant to determine the direction of interview (Stuckey, 2013) while still following an interview schedule (see Figure 1). The interview schedule set up a narrative trajectory from pre-diagnosis to the present, including concerns for the future. Participants were asked about a range of topics relating to their experiences as a carer of a CWE and of the epilepsy service. A professional service was used for the majority of transcription, with transcripts then being checked for accuracy and anonymised. It should be noticed that the material gained from this comprehensive interview went far wider than interactions with

services. We considered it necessary to conduct interviews in this way to aid memory for experiences that were sometimes relatively remote in time, and this framing additionally meant that our focus on service comparison was not made explicit.

5.3.3 Analysis

The interview transcripts were subject to Thematic Analysis following the process outlined by Braun and Clarke (2006), which is described above. A realist epistemological position was adopted. The content of 20 of the interviews across ESN and non-ESN areas were inductively coded, ten for each type of area. Coding at this stage was exhaustive and inclusive. Codes were developed and checked in discussion with CW and ARL (supervisors) to ensure that they reflected the content of the data. Coding was done using NVivo 12 qualitative analysis software (for a list of codes pertaining to the whole data set, please see appendix 3). For the purposes of this analysis, those codes that related to the carers' relationship with the epilepsy service were then applied to the remainder of the data set. Those codes and the data located under them were then reviewed by the research team to identify potential themes, i.e., codes which related to a recurring feature of carers' experiences. These themes were reviewed to ensure that they were internally coherent, distinct from each other, and offered an insight into carers' relationships with epilepsy services. The results and discussion for this study will be presented in the following chapter.

Figure 5.1

Interview Schedule

1) When did you first notice something was wrong? or Could you tell me about how it all began? (What happened? What did you do? How did you feel?) Within this find out type of Epilepsy, type of seizures, age of onset, circumstances of first seizure.
2) Could you tell me about your first encounters with the health services in relation to your child's epilepsy? (Hospital/ A&E, GP visit and referral, etc) If hospitalised, discuss experience of A&E, test conducted, doctors involved, information given, treatment on the ward, circumstances around being discharged and follow-up.
3) Before any of this happened did you know much about Epilepsy?
4) When did you first meet your consultant? Do you remember the appointment with the paediatrician, would you talk me through that appointment? Who was there, what was said, etc.
5) What sort of information did they give you about epilepsy? May cover diagnosis, prognosis, social implications, other issues?
6) Where you given medication/ when were you given medication? Where they told about side effects/ administration/ dosage, etc? Rescue medication? Any training?
7) Do you see anyone else in clinic? (fact finding re. ESNs, other nurses, etc).
8) How often do you see your consultant? What things would/do you contact them about? If you needed to speak to them outside of routine appointments how would you make contact- phone, email, text?
9) If ESN area- When did they first meet the ESN? What did they explain about their role? Have you contacted them? What for? Are they accessible? Do you have direct contact details for them?
10) (Co-morbidities) If not already mentioned- What difficulties does your child face that are directly due to the epilepsy? (This may already have been answered during explanations to the above questions). Do they have a diagnosis of any other condition? What difficulties do they have that are related to their other diagnosis/conditions and not due to the epilepsy?
11) If relevant- How have things been at school/nursery/college? What support have you received for your child's condition? Has the Epilepsy service- helped with that/ been into school/ been in contact with school? (e.g. training in school of condition and/or rescue medications, care plan, etc.)
12) If relevant- How are they doing at school? Any issues with academic performance, memory, concentration? Do they think it is due to the epilepsy or the medication?
13) How has the Epilepsy affected your family in terms of social life, activities, days out/holidays? Are there things- that are different now, that you wouldn't do, that you restrict- due to the Epilepsy?
14) How have *you* coped? How have your family/friends been about it all? If relevant- how has it been with working?
15) Have you accessed any other Epilepsy support services? (Charities, support groups, online forums, helplines etc). Where did you hear about them? Has it helped?
16) If relevant (as can be sensitive issue)- Do you think about the future? or Do you have concerns about the future? What has been discussed with your consultant about the future?
17) What things about the epilepsy have you found most difficult? Is there anything that would make this easier?
18) In terms of the Epilepsy service, so that's anyone you may have seen at clinic and the rest of the team there- What would you say are the best things about the service? In your opinion, is there anything that could be improved?
19) Thank you, that's all of the questions I had for you, is there anything you think I haven't covered or anything you would like to add?

Chapter Six: Carer Perceptions of Paediatric Epilepsy Services- Results of A Thematic Analysis

Within talk of participants' relationships and experiences with services, four themes relating to different aspects of carer's needs were identified (see Figure 6.1). These were needs for *understanding the condition*, *condition management support*, *educational liaison support*, and *emotional support*. The analysis for each will be outlined and explained with excerpts from the transcripts to illustrate points, prior to discussion. A shorter version of the analysis has previously been published (Beesley et al., 2022).

Figure 6.1

Table of themes

Theme	Codes
Understanding the condition	• Experiences of consultant Additional support (outside epilepsy service) Diagnosis Explanation and information about medication Explanation of condition Written information provided • Experience of ESN • Parental understanding of condition
Condition management support	• ESN influence in consultation appointments • Support and training with medication • Experiences of acting ESN • Experiences of Consultant Accessibility and availability Treatment and care plan (ongoing) • Experience of ESN • Medication management Rescue medication • Parent management of condition
Educational liaison support	• Practical support and training • Support and training with medication

	• Experience of Consultant Treatment and care plan (ongoing) • Experience of ESN • Experiences in school or nursery Training not by ESN • Educational support in school
Emotional support	• Effect on parents • Experience of ESN • Parent's feelings post-diagnosis

Note. A full list of codes can be found in Appendix 3.

6.1 Theme 1: Understanding the condition

There were many instances, across both ESN and non-ESN areas, of parents/carers reporting valued experiences of having the diagnosis and treatment explained to them thoroughly and carefully. The need for understanding was ongoing (Nevin et al., 2020), and ability to ask questions in interactions and consultations was key to this. Parents/carers valued the time the medical professionals spent with them, the expert knowledge available to them and the reassurance they received. Parents/carers were able to leave the appointments feeling that all their questions had been answered, they had a better understanding of the condition and were confident that they understood what to do if certain situations occurred.

"He (paediatrician) took the time. He did all these little drawings for me. Because I was just, like, "I don't really understand this," you know. So he took the time to explain." (AREA 3, 014)

"It felt like when you sit down and you speak to… (paediatrician) he/she knows exactly what he/she is talking about" (AREA 4, 013)

"(Name of ESN) just absolutely answered all my questions. All the questions I had, he/she answered everything that- and I've got nothing in my head saying, "What if this happens? What do I do? What if this happens?" …and he/she has made my life easy. I can tell you that." (AREA 1, 042)

The respondents' individual relationship with, and desire for, information varied considerably. In the following example, the respondent appears to contradict themselves

in terms of how much information they were given, but this becomes comprehensible when considering that their focus was on the extent of treatment available, rather than understanding the condition itself.

Interviewer: So that first appointment you had with (name of first Consultant), the clinician up there, what sorts of things were discussed then, at the initial..?

Respondent: Oh, gosh. Not a lot, really. Just that they'd try to control his seizures.

Interviewer: Did he sit and explain what epilepsy was in detail?

Respondent: Yes, he will have done. I can remember him spending a lot of time. We came away sort of shell-shocked, but still thinking – well, I certainly thought – that the drugs would help him and he'd stop having the seizures. I really did. (AREA 4, 005)

The issue of the emotional state of the parents/carers during that initial meeting and post-diagnosis, as in the excerpt above, was one that recurred across the interviews. Interviewees frequently reported that the affective impact of the diagnosis (even when it was anticipated) was sufficient to disrupt their ability to take in and recall information provided during that initial conversation. Consequently, even in services where the level of informational support was generally reported to be excellent, interviewees identified written, rather than verbal, information as potentially more useful to them, given the disruptive impacts of their emotional responses to the diagnosis. In one area in particular, carers were encouraged to seek information from the Epilepsy Action (EA) website, and were also given printed materials from EA.

Several respondents from across the areas reported utilising chat groups such as those from Young Epilepsy, as well as having contacted EA. While generally valued, some parents felt ambivalent about the knowledge gained.

"...we did a bit of internet searching which I think was counterproductive at times because it just served to utterly put the fear of God in me about what the future held." (AREA 2, 013)

One ESN maintained a Facebook page as a conduit of advice and to generate community:

"But (Name of ESN) is great. They're great… They've got an epilepsy Facebook page. So things like- …Little bits about sunshine, about epilepsy and Vitamin D deficiency. There are all sorts of things that they put on, and it is quite interesting and quite useful." (AREA 2, 005)

Some carers relied on online support groups, especially in non-ESN areas:

"It's just asking other parents and other people how they cope, or finding information about where to go and what to do. It's amazing how little you get told about things and what support there is." (AREA 4, 010)

From the parent's perspective, there is a difficulty in determining what they need to know, and what is not relevant to them and their child (Lewis at al., 2010), and this presents problems when accessing external sources of information, such as that posted by charities on their websites, or that shared by parents through social media (McNelis et al., 2007). In a minority of cases, information accessed from those sources was experienced as overwhelming, confusing, or frightening in terms of the possible futures for their child. Online support groups may serve as a solution to this issue. Discussions with other parents with experience of specific issues may provide parents/carers with answers to questions they didn't know they had as they identify new areas of concern.

Interviewer: Did you go away and do your own research or…

Respondent: I did go onto the epilepsy UK website and things and I did join and I started getting the magazine and things.

Interviewer: Who was that from?

Respondent: From Epilepsy UK. Or is it Epilepsy… the pink and blue… Epilepsy Action. I started getting their magazine and things but-

Interviewer: Did you find that useful?

Respondent: I probably found it more frightening, actually. It probably did the reverse for me. It probably did the… It was almost too much information with not enough knowledge about (child's name). I didn't know which bit (child's name) fitted into. We'd never had the terms like tonic-clonic or none of those terms were ever used so I'm not sure, even now, what type of seizure it is that (child's name) actually has. (AREA 4, 001)

For a parent or carer moving towards autonomy in the management of their child's epilepsy, there are moments when a gap in their knowledge is identified, typically when they do not know what to do in a particular situation, and consequently they need to seek support. This tension between information deficit and information overload may contribute to online sources of support being perceived as overwhelming, as the terminological and technical knowledge of the condition needed to navigate such resources is missing. Such gaps in knowledge could be experienced as insufficient information having been provided. However, in ESN areas where the service is experienced as accessible, the accessibility of the ESN mitigates perceptions of insufficient information provision; the information is perceived as timely and responsive to the parent's and child's needs. For clinicians and nurses, information provision at the time of diagnosis is therefore a fine balancing act; the volume of information provided should be sensitive to the parent's affective state and their consequent capacity to take onboard information, and the topics and terms on and about which information is provided should be tailored to the child, their needs and circumstances, at that point in time.

"I would say that [being able to contact the ESN] was the most invaluable resource at the time of going through diagnosis and (Child's name) then being on medication. Because things didn't go to plan, and there were times where I had to ring up. Having that expertise, who knows (Child's name), at the other end of the phone, rather than just going off to A&E, that was invaluable then." (AREA 3, 024)

However, as evident in the excerpt below, the provision of information that targets immediate needs can have the potential to create a problem, i.e., that clinicians and nurses, in determining what a parent or carer needs to know now, might choose not

to inform the parent/carer about some aspect of epilepsy that subsequently the parent/carer does need to know more about. This highlights the importance of ongoing informational support as a key feature of a service that is experienced as accessible and supportive.

Respondent: Yes. So it's scary. So my anxiety is still there, until next year really, until I know what's happening. Until I know that if he's going to be seizure free or if he's going to have a seizure or...

Interviewer: Have you spoken to anyone about the fact you feel like that?

Respondent: I have. I have spoken to (paediatrician on Consultant's team) and (name of ESN), and (paediatrician on Consultant's team) was saying that near enough to the time we'll have another chat, but she's going to call us again and have another chat and she said we'll see. And if you think that that's not the right time yet, we can leave it for a little bit longer. But what- I mean, they are good. So they know what you're feeling, and (paediatrician on Consultant's team) and (name of ESN). They know what you're feeling. (AREA 1, 042)

Overall, this theme highlights how the perceived sufficiency of information provision is largely contingent on immediate circumstances and needs. Parents dealing with a child newly diagnosed with epilepsy need to know what it means for their child, hence the emphasis on explanations of epilepsy and how it can effectively be managed. Neither parents, clinicians or nurses can predict the child's future needs and so might seek or provide information selectively according to their perceptions of the child's, and the family's, likely future needs. From the clinician/nurse perspective, there is also a need to avoid providing information that is redundant or might prove not to be relevant to that child or their parents. Similarly, from the parent's perspective, there is a difficulty in determining what they need to know, and what is not relevant to them and their child, and this presents problems when accessing external sources of information, such as that posted by charities on their websites, or that shared by parents through social media. Information accessed from those sources can be experienced as overwhelming, confusing, or frightening in terms of the possible futures for their child.

Good quality informational provision mitigates uncertainty and thereby anxiety. Therefore, high quality informational provision serves emotional support functions.

6.2 Theme 2: Condition management support

Once the diagnostic and initial treatment phase has occurred, carers are provided with instruction on how to manage their child's epilepsy. Part of this instruction involves the service outlining the kinds of situations in which they should seek advice and help from services, or indeed take some form of emergency action, such as rescue medication administration, or seek help from the emergency services by way of a call to 999 or 111.

Interviewer: When you used to contact the epilepsy nurse in (name of Children's hospital), what kind of things would you contact them about?

Respondent: It was usually the time where (Child's name) was either being introduced to a new medication or weaned off, and maybe we couldn't move on to the next stage because his seizures had increased, so we had to stay on that stage or go back to the previous one. It was mainly around that. Yes, around seizure increase really.

Interviewer: Do you know, looking back now specifically, what made those conversations and that support helpful, in terms of what the nurse said or did?

Respondent: Well, the knowledge, at the time, at the other end of the phone. It would have been the reassurance of acknowledging what I had said, and either go back to the previous stage, and just that direction of what to do. (AREA 3, 024)

This level of support allowed parents/carers to feel reassured they are doing things correctly and instilled confidence in managing their child's condition. The clarity and open-endedness of these instructions provided for the carer's subjective experience of the service as an accessible and supportive one; with the most supportive opportunity being an open invitation to contact.

"She told us that that was her role. She was the nurse. She gave me her business card with her phone number on. Then she gave me a handwritten one, with a mobile number on." (AREA 1, 033)

"If I do need anything, or have any questions, I can just phone (ESN's name), or just even text (ESN's name), and they always get back to me. They'll speak to (Consultant's name), and they (ESN) always gets back to me. Even at the initial point… there used to be times when I was phoning up (ESN's name) saying, "He's not had his medicine. He just won't take it." We've always had that kind of support." (AREA 1, 022)

Parents reported being able to "just phone" or text ESNs with "any questions". Being able to approach an ESN about things that they did not understand or which they deemed important helped them to feel confident that their concerns would be acknowledged and dealt with appropriately. They also recognised the level of specialist knowledge available to them as a benefit of the close working relationship between an ESN and a consultant. When they contacted an ESN they appreciated not only the high level of expertise and experience of a nurse, but the nurse's access to the consultant to seek further information or even a second opinion. Parents/carers also noted services had been accessible from the "initial point" suggesting ESNs have historic familiarity with the families and that there has been continuity of care to establish these relationships.

"With (ESN's name) we're quite lucky, in the fact that because of the relationship as well that we have with (consultant's name), and (ESN's name) and (consultant's name) work very closely together, if we're concerned about anything, or (child's name) has had a series of these, we tend to always let them (ESN) know. And they're happy for us to contact them (ESN), to get in touch with them (ESN), whether via mobile or we can just leave them a message." (AREA 1, 015).

In ESN areas, parents/carers expressed satisfaction with the service and commented on the good relationship they experience with both the consultant and the ESN. They reported feeling "lucky" to have this relationship and that it was valued by them. This relationship was grounded in trust and perceived mutual respect. When they had concerns, parents/carers felt confident enough to raise them, knowing they would be taken seriously. The ESN had previously expressed a willingness to be contacted, and s parents/carers felt able to do this through a variety of mediums. There was no apprehension or worry about wasting the ESNs time. This level of relationship allows

parents to feel that their concerns and question are valid and would not therefore be ignored, rejected or judged.

Interviewer: What things have you found useful and good about the service?
Respondent: I think the fact of having that phone number that you can contact. I think that's incredibly useful. That you know someone is there at the end of the phone, and if you leave a message, you can ring. They'll call you back. (AREA 1, 028).

Even at the end of the interviews when asked for positive evaluation of the service with questions such as "what would say were the best things?" or what was "good about the service?" parents regularly stated the ongoing contact with services above all other factors. The idea that "someone is there at the end of the phone" provided valuable reassurance that there is safety net, and they do not need to navigate uncertainty and challenges in managing the condition alone. This aids the development of emotional resilience, confidence and, ultimately, autonomy in managing their child's condition.

Parents also noted the benefits of having alternative methods of contact. Most parents talked about being able to phone the ESN directly on their mobile phone number. They could use this to either have impromptu conversations if the nurse was available or they could leave a message. Some parents preferred being able to send a text message where they could give a brief outline of the issue. This would either result in a text response with an answer or, if the ESN deemed it appropriate, they would call them for a fuller discussion and explanation. Interestingly, some parents preferred email contact. As described in the excerpt below, this allowed the parent to make contact at a time that was suitable to them. This was an important means of communication as it provided the opportunity for the parent to give more expansive explanations of situations that were concerning to them and of which they wanted the epilepsy team to be aware. For example, if a parent wanted to give a detailed account of the child's behaviour following a medication change this may be difficult to do in an appointment

if their child was in attendance. Where children are young enough to need their attention or if they are of an age where it may not be appropriate to describe fully in their presence, the parent might feel flustered or under pressure and unable to give full or detailed account of the issue. Having email as a communication option offered the parent a unique opportunity to fully outline any issues in the calmness of their own environment, at a time to suit them. This provided the opportunity for the parent to feel heard and for the professionals to receive a level of detail that may not have been available to them through other modes of communication.

"I did have her email address, but I haven't got that any more. But that was really useful. Because when I'm doing things, I might do things late at night, you know, when everybody's in bed, and it's quiet, and I want to tap, tap, tap, that's really, sort of, useful. I think just that person that you know, if you've got a question, you can ring them up and they'll help answer." (AREA 1, 028)

Some ESNs visited patients in their homes which was highly valued. Visits were not only appreciated in a practical sense and aiding the sense of accessibility but seemed also to contribute to rapport building.

Respondent: Yes. Well, we've seen her up at the (name of health centre) and she's actually come to the house and seen him and done the appointment that way as well.

Interviewer: How have you found that?

Respondent: She's great, (name of ESN). She's really flexible. She's brilliant with (Child's name), and she really just gets to know you. She's really nice. When she came here to the house that day she was talking to somebody across the street before she come and knocked on. It turned out it was one of her other patients, but her son, he kept refusing to take his medication and that. Anyway, yes, but she is, she's really good. (AREA 1, 033)

This contrasts with those parents who experience services as less accessible, owing to limited methods of contact and ambiguity as to the problems they are expected to manage autonomously versus those where it is expected that service contact should be made. In the following excerpt, the respondent contrasts the situation before and after the ESN joining the service.

Interviewer: So were there times where you did want somebody to ring?

Respondent: Oh yes.

Interviewer: Can you give me a bit of an idea?

Respondent: When the medication wasn't working and no one to ask really. I just had to wait for the next appointment, but it shouldn't be on that really. …

Interviewer: Did you try at any point to contact in between the six months?

Respondent: I tried yes but obviously they're busy aren't they? … They managed to squeeze us in a few days after. It's only happened twice, that. With having this epilepsy nurse to ring it's not too bad now. I can ring her any time, you see. (AREA 3, 025)

There were also differences observed within ESN services. Some parents reported that they were not given contact details for the ESN. These parents were unable to contact an ESN directly and would have to find other ways of getting messages to them.

Interviewer: Have you got a number or contact details, if you needed to speak to them (ESN)?

Respondent: No, I've never been given any details for them, no. I just thought if I ever have any problems I just used to ring Dr (consultant's name) up, but it used to take them a couple of days before I'd get my response. (AREA 3, 015)

Parents also noted difficulties in accessing support when the clinicians were on leave, suggesting a lack of interim support services to cover absences.

"I think sometimes there's a little bit of a, it's not either their (consultant) or (name of ESN)'s fault, but it just seems if they weren't there or they're on holiday there's nobody that we can get in contact with. I think that's what we find quite difficult. Sometimes we text (name of ESN) and she's been on holiday which is, everyone's entitled to holiday. But it goes from being really good when they're there to nothing, really." (AREA 1, 004).

Across the interviews, carers oriented to the knowledge and authority statuses of the points of contact, and these perceptions impacted on their perceived right to initiate contact and seek support. Simply put, secretaries and nurses, including ESNs, were perceived as more accessible to carers than were consultants. But, the knowledge status

of ESNs, relative to other accessible contacts, meant they were perceived as having sufficient authority to validate concerns, endorse courses of action already adopted, and/or recommend alternatives. It is these factors that lend to services with an ESN being experienced more positively as accessible, and as supporting the parent in their trajectory towards optimal management of their child's epilepsy.

"Basically (ESN) said, "If you've ever got any problems with him and you're not sure, just give us a ring." That was nice, just thinking, well, rather than having to bother the GP with something that might be trivial…"(AREA 2, 005)

In areas without ESNs, other professionals were often reported as taking on responsive roles, in some cases as going to extreme lengths to make themselves available outside of clinic appointments.

"But, to be honest, we've had really good communication with our community paediatrician. And [he/she] is like, "If you just ring up at 8 o'clock in the morning and ask to be put through to me, I'm there at that time before my clinic starts if you've ever got any concerns or anything". So I could always ring [him/her] up. And [he/she] did adjust the medication over the phone and put me a prescription out if we needed it..." (AREA 4, 016)

There were differences in accessibility of no-ESN services. Some parents noted that when they tried to contact services they would receive return calls to offer support.

"Yes, I've always had his (paediatrician) contact number, and he always gets back to me. I mean, my wife always thinks he doesn't get back quick enough, but for me, in the job he does, and the up and down, and the amount of children he sees, he always gets back the next day at the latest." (AREA 5, 006)

However, for some patients a delay in response or lack of direct contact with the service would cause difficulties, depending on the nature of the issue. One respondent reported having to reach the paediatrician via the GP.

"I think it was always (Consultant paediatrician's name) that would say, 'That's not worked,' but you don't immediately get back into the appointment system; you have to go through the GP…he came out in hives all over his body…and it tells you take them off immediately and go to your GP…and then they would send a note through to the hospital, and in the meantime then you wouldn't be taking any drugs, because they'd tell you take him off them so then you'd wait for another appointment to see them." (AREA 4, 014)

This theme highlights the ongoing need for ongoing support in managing the condition. As epilepsy is not a static condition, so support needs change and parents and carers must adapt over time as the child develops. Access to ongoing support is essential as new challenges arise. Services with ESNs are experienced as accessible and overall more positive as they proactively seek to support parents/carers. In contrast services without ESN support are experienced as providing parents/carers with condition management support on an ad hoc basis balanced against other workload responsibilities. This leads to differences in how services are experienced in terms of ongoing condition management support. From the carers perspective, methods of contact, ease and directness of contact, timeliness of response and continuity of care all contribute to the overall experience of ongoing support from the service.

6.3 Theme 3: Educational liaison support

The two main functions in terms of educational liaison that respondents talked of were the training of staff to manage seizures, including action steps in case of a prolonged seizure, and participation in review meetings of special educational needs (SEN) provisions. The talk in ESN areas often captured a pre-emptive approach in which it was clear that the ESN would both take responsibility for these functions and had made clear to parents that such responsibilities were part of their remit.

"Yes and (ESN) said, "If you need me to, I'll do a care plan, if you need me to come into the school, I'll come and meet the school." (AREA 2, 005)

[describing special educational needs review meeting] "So I can't fault them on... In fact, (ESN) was the one who said "No, actually he's got this, this and this." And the educational psychologist didn't know…I've got to give (ESN's name) ten out of ten for the last meeting." (AREA 1, 030)

ESNs were reported as proactively arranging to go into schools, clubs and extra-curricular activities to train any professionals with whom the child came into contact to ensure their epilepsy was managed appropriately while in their care. This not only

alleviated the burden from the parent of arranging or providing training but also boosted their confidence in leaving their child in the care of people who had been trained by a professional to competently deal with a medical event.

"It's a real plus that she's gone into school, preparing all the staff and, "Tell me if there's anything else, if there's any other specialists or professionals working with (Child's name) who needs training." She's offered services to... He's got a care service at the moment it's working with a programme. She's offered services to them, to train their stuff up about how to deal with (Child's name) when he has fits and things like that. (AREA 1, 016)

There were also a few examples of carer-initiated school interventions where the ESN took wider actions to inform others and thereby promote better support for the child with epilepsy. This is illustrated in the excerpt below, where the parent had requested that the ESN give a talk to the child's class, while the child was absent, so that a more understanding environment would be created.

Interviewer: Did anything change or did you notice anything after (name of ESN) gone in and chatted to the kids? Did that have an effect, do you think?

Respondent: I think it did, from what (name of child's teacher) said. It made them think about (Child's name) a little bit more, if he needs a little bit of help or conscious of when he does have a dream that he's not hurting himself, that kind of thing. (AREA 1, 041)

ESNs also supported parents/carers in wider educational issues beyond epilepsy. Their support as liaison with other services was valued by parents/carers who already faced many challenges in managing the condition. ESNs were a vital support to and advocate for families in navigating services with which they were unfamiliar.

Interviewer: Did you get any support from the Epilepsy Service in terms of helping him integrate back into school or help getting a statement and that kind of thing?

Respondent: (name of Consultant) and Dr (name of paediatrician) were brilliant. I mean, they made sure they kept chasing it up with educational... in the education department, Children's Services, to make sure that he gets seen to. A psychologist... a children's psychologist to get a statement in. They kept putting pressure on him to get it done as soon as, so he could get that support in school. (AREA 1, 016)

In contrast, respondents from no-ESN areas reported being in a position of having to seek or arrange training, with ad hoc and less positive outcomes. In the example below, the carer reported initially being asked by the nursery to provide seizure management training, but did not feel able to do this; fortunately, from the parental perspective in this case the nursery ultimately took responsibility for provision.

"…when she started nursery, because there was no…epilepsy nurse, there was nobody to give training to those staff. So actually out of the good will, her nursery paid for quite a lot of their staff to have epilepsy training, which was really, really good, for the buccal midazolam." (AREA 4, 010)

Attendance at review meetings to determine special educational need support was reported as valuable to parents/carers. Unfortunately, it is not always possible for a member of the epilepsy team to be available. Although parents/carers are well placed to advocate for their child, they lack the medical expertise and understanding of additional needs, which may be relevant in these situations, to ensure the CWE is referred for all the support they may need. In the following excerpt although the paediatrician clearly intended to attend, they were ultimately unable to, leaving the parent/carer or other professionals to fill the void.

"…people get busy, don't they, I suppose. But her annual review meeting …that year (paediatrician) was going to come because of all these issues. But then I don't think he/she could make it in the end. But he/she did write a letter…" (AREA 4, 016)

During the interviews additional concerns were raised by some parents. The importance of various support services working together and communicating about the child's needs was raised. This extended beyond the scope of work done by the ESN and warrants further investigation. For children with complex needs and or comorbid conditions, epilepsy is only one aspect of their care needs. Parents/carers would benefit from improved communication from those supporting additional educational, behavioural and social needs. ESNs are able to support the parents/carers in epilepsy

related needs however, for certain issues, a wider team around the child is needed for parents to feel supported.

For me, basically, as soon as it's identified, especially with young people, services needed, if someone to take the lead in ensuring you are getting professionals on that table to support and meet the needs of the person concerned. I think, for me, that's been a real, real struggle. Even now, even though the support is there, there's no one to coordinate the services. It still me as a parent. I'm constantly on the phone trying to make calls and things like that to get people to take responsibility even then, it's like, "Can the learning and disability team come today? He's been working with (Child's name) about his anger." "Oh, can you let the social worker know we're going to be exiting because (Child's name) has left school?" "Can't you liaise with them?"…… As a parent, it is quite frustrating. I think you have to sit on a table- even if it's only once every term, every quarter or something and just make sure that professionals are being challenged, that support is there. (AREA 1, 016)

ESN provision and the facility for ESNs to take on responsibilities for educational liaison are clearly valued by carers. The ESN's status as an expert on both epilepsy in general and on the specific needs of the child in question represent a critical resource for parents in helping to secure adequate support, and in creating a wider environment that is sensitive to and understanding of that child's needs. The absence of ESNs, and the consequent absence of that proactive support, leave parents to formulate ad hoc solutions; a situation that they find stressful given their relatively lower knowledge status. The support of an ESN also alleviates an emotional burden from parents that can arise from interacting with services. In areas without ESN support other clinicians are well placed to support parents in a liaison role, however, due to time constraints and workload responsibilities, it is not always possible.

6.4 Theme 4: Emotional support

The interviews were often highly emotionally charged, with respondents finding the recounting of their family epilepsy story a powerful and emotive experience. This was crystalised by one carer citing the interview itself in their response to being asked about the best aspects of the service they had received. For some parents/carers there is

a clear need and desire to discuss their challenges and difficulties. This may serve to help carers feel less isolated and alone in the circumstances they face caring for their CWE.

"Interviewer: In terms of the service that you received so that's from the epilepsy team, what have been the best things about the service, what things have you found good?

Respondent: You sit down and talk to us." (AREA 4, 011)

In ESN areas, some respondents did refer to the emotional support they had experienced from the service and identified it a highly valued on the basis that the ESN both proactively demonstrated concern for their emotional well-being and represented a source of emotional support.

"Interviewer: Would you say that, in terms of the professionals involved, would you say you have had some support for yourself there?

Respondent: Yes. They've been brilliant. They always ask how I feel as well, to make sure I'm all right with the next plan, and make sure I'm happy. (name of ESN), they'll talk to me and they'll say, "Are you all right?" If I ring and say that (child's name)'s had so many seizures in a day, or whatever, the first thing they'll ask is, "Are you all right?" Make sure that I'm calm and coping." (AREA 3, 017)

(name of ESN), the epilepsy nurse, was a gem. She was absolutely and she is absolutely brilliant. I think everybody should have a nurse like (name of ESN). She is absolutely fantastic. It's like- she's a rock. And I was just so down. I didn't know who to speak to until (name of ESN) came into my life. It was- she pictured like a bright light for me. I was just so down, you just wouldn't believe.

Interviewer: Yes.

Respondent: Because you need that person- you need somebody to talk to, you know, like the pain that you're going through. But I didn't have that for such-.

Interviewer: And someone that'll understand as well.

Respondent: Exactly. You need someone who can understand what you're going through. But (name of ESN)- when I have problems or when I feel there's something not right, I ring (name of ESN) up, and the home visits that she does, honest to god, it's just heaven sent. She is just a brilliant- everybody should have (name of ESN), I'm telling you. I'm telling you everybody should have (name of ESN). (AREA 1, 042)

Throughout the interviews there was a clear sense that the carers' experiences of the management of their child's epilepsy involved a complex set of emotional responses, from profound fear about the present and future well-being of their child, to anger at responses (or lack of response) from others, to the aspiration for relief and happiness at their child being declared seizure-free. Whilst information provision and practical interventions supported carers in the management of their child's epilepsy, many carers clearly experienced a need for emotional support, and placed a particular value on this support coming from someone whom they perceived as fully appreciating their specific circumstances.

Interviewer: So overall, if you were to sum things up, what help had he/ she given you, the epilepsy nurse, that you felt was useful?

Respondent: I felt I could talk to him/her about how it makes me, as a parent, feel. I can't talk to (name of Consultant) like that.

Interviewer: So it wasn't just the medical bits; it was more support around it as well.

Respondent: No. When you're scared – as a parent, you're scared about your child – I could tell him/her that, and he/she'd listen. But with (name of Consultant), it's just very cut and dried: "He's epileptic. There's his medications. (AREA 4, 005)

Respondent: [ESN] They always ask how I feel as well, to make sure I'm all right with the next plan, and make sure I'm happy. (name of ESN), he/she'll talk to me and he/she'll say, "Are you all right?" If I ring and say that (child's name)'s had so many seizures in a day, or whatever, the first thing he/she'll ask is, "Are you all right?" Make sure that I'm calm and coping. (AREA 3, 017)

In contrast, other respondents felt that emotional support was not something they could or should expect from the professionals within the epilepsy service. The roles and statuses of professionals, as well as an appreciation of their workloads, mitigated the extent to which some carers experienced seeking emotional support from them as legitimate and appropriate.

"Because I know they're there, but would I really want to ring up a nurse, and start blooming crying down the phone to him/her? You know, not because, just because I'm

sure he/she's very busy, you know what I mean, and that's not what I see him/her as being there for." (AREA 3, 020)

There were several interviews where respondents had an overtly stoical approach to their situation, and it was clear that they would not have wanted emotional support from services, as the quote below exemplifies:

"We're kind of a family where we don't, I don't know, we just get on with it. If there's an issue we just deal with it. We don't go crying off to other people, do we, we just get on with it." (AREA 4, 013)

Some parents felt equipped to cope with their circumstances without the need for emotional support, although they did struggle initially. However, they noted the information given and their subsequent understanding of the condition aided this process. Although they reported that they did not feel a need to contact anyone for emotional support they conceded that they would have felt comfortable approaching the ESN.

Interviewer: Same question for you. How have you found it all? How have you coped with it?

Respondent: Absolutely fine. But I'm a bit like that. I tend to deal with what I'm dealt. You just do. I just think, "Well, this is it. We can't change it." A little bit difficult in the beginning, when she was manic. Not quite knowing how to do it. Struggled with the upset of it. Really struggled with her being so upset about it. But now I'm absolutely fine. I'm absolutely fine, because I understand it, and I know what's happening, and I know it's not life- threatening. Provided it's under control, it's not life-threatening…..

Interviewer: Have you ever felt you needed to talk to anyone, or was there anything about it that you struggled with?

Respondent: No. If I had done I would have rung (name of ESN). (AREA 1, 033)

However, for parents/carers who did need emotional support, the ESNs were highly valued. For some parents/carers, the unique position the ESN holds in both a caring role and a highly trained medical professional, bridges the gap of both

informational and emotional support, which provides reassurance and confidence that the parent/carer has access to whatever support they need (Hopkins & Irvine, 2012).

Respondent: No matter what I say about (name of ESN), it's not enough. She is such a fantastic nurse, and so fantastic, and you need somebody. When you're going through this stage, you need somebody, especially a nurse that- I mean, (name of ESN) is specialised in this. So you need somebody who understands you who can relate what's going on and how you're feeling….. You need that visit, a home visit, because then you can open up. The things that you're going through, you can open up to her, and she's not like just a nurse or she's doing her job. She's more of a friend, and she's more of a friend. And when you're doing your job, it's just a job that you're doing. Well, she goes out of her way. She makes it easy for you. She tells you about everything, what's going to happen, what's happening, like, "It will calm down." She's just there.

Interviewer: The reassurance.

Respondent: She reassures me all the time, and I can't say any- like I said, if I say- I've got so much feelings for (name of ESN) that she's done so much for me. It's like without her, like I said, without her, I don't think so. You need a nurse. You need a nurse like (name of ESN) everywhere. (AREA 1, 042)

6.5 Discussion

The unique value of the ESN from the carer's perspective that emerged from our interview data lay in their holistic knowledge of the CWE and their family, together with their ability to advise and advocate for the CWE, due to their professional knowledge and status within epilepsy services. The support offered by ESNs helped to establish a sense of collaboration between the carer and the epilepsy service. The ESN was able to meet the different support needs of families proactively and sensitively, whereas in services without ESNs, carers were left to fulfil needs across diverse contexts in an ad hoc manner (Beesley et al., 2021).

Generally, parents/carers reported positive experiences of explanations and information received at diagnosis from paediatricians, both in ESN and non-ESN areas (Theme 1). Parents/carers expressed an ongoing need for information in order to understand the condition. The ability to ask questions during interactions and consultations was key to them feeling supported by services. Parents/carers valued the

time, knowledge and reassurance they received from medical professionals. Access to information from online and other sources was sometimes perceived as confusing and worrying given the tension from the parent's perspective, in navigating what they need to know, and what is not relevant. Support from other parents could sometimes aid in this but ultimately good quality information from the epilepsy service could mitigate these fears. It was also apparent that emotional responses impede capacity to take on board information given verbally during consultations, with written information being found to be especially useful during these stages. There is also a tension between information overload and information deficit which clinicians need to carefully balance to ensure parents/carers feel informed without being overwhelmed (Jones et al., 2019).

Differences occurred in terms of on-going condition management support (Theme 2) wherein the open invitation by ESNs for contact to address unexpected situations and queries contrasted with non-ESN services, where carers were unsure of the circumstances under which it was "allowable" to contact clinicians between regular appointments. Many parents/carers with access to ESNs felt a high level of access to support. They felt comfortable and able to contact someone when they had concerns or questions. There were various options for contact provided, including direct mobile phone number, text and email. This contrasted with parents/carers from areas without an ESN who had difficulties knowing how to contact, or "didn't want to bother", medical professionals when they needed additional support. Additionally, the perceptions that respondents had of the different roles within clinical teams constrained what they felt they could ask of the different professionals involved in the care of their CWE. These results are consistent with the findings of Williams and colleagues (2018) whereby the perceived accessibility of services was by far the largest predictor of carer satisfaction, with services with paediatric ESNs being perceived as more accessible. Overall,

ongoing condition management support provides reassurance and instils confidence in parents/carers in managing their child's condition.

As well as the direct emotional support offered by ESNs (theme 4), there was a reduction of emotional burden and stress occurring from having accessible and ongoing support (Theme 2), and from not having full responsibility for liaising with educational and other support services (Theme 3). Both qualitative (Smith et al., 2014) and quantitative research (Jones & Reilly, 2016), suggests that this ongoing level of responsibility adds to carer burden and can be mitigated by professional and social support (Austin & Caplan, 2007). However, as Jones and Reilly (2016) point out in their systematic review of parental anxiety in paediatric epilepsy, there are as yet no studies of either group or individual psychological interventions, such as cognitive behaviour therapy, aimed at carers of CWE. Such interventions may be required to have a measurable impact on the elevated levels of depression and anxiety found in carers of CWE (Shore et al., 2002). ESNs cannot be expected to provide such specialised psychological interventions in addition to their clinical and liaison roles.

6.5.1 Strengths and limitations

A methodological strength of this study was the interview schedule (see Chapter 5, Figure 5.1) that was devised specifically for this research. It was comprehensive and captured a range of data beyond the scope of this study. A narrative/chronological approach was used, starting with the first instance or event when the parent/carer thought or knew something was wrong, before moving through discussion of diagnosis, prior knowledge of epilepsy, experiences with the clinical team, notable appointments, medication, contact with services, specific questions about the ESN (if applicable), co-morbidities, additional events or issues with school/nursery/college, social consequences, impact to the family, liaising with outside services, epilepsy support,

coping and concerns/fears for the future. This allowed for a more naturalistic and conversational interview with the participant telling their stories of experiences and memories which were rich in detail. Each interview ended with some evaluative questions about the best parts of the epilepsy service and what could be improved, and all participants were given the opportunity to add additional comments or detail if they felt anything about their overall experience had been missed. This approach allowed for a participant-directed interview, in the true sense of a semi-structured interview, where deviation from the questions was encouraged when the participant had something meaningful to add. In cases where the participant unknowingly covered topics or issues that might otherwise have been covered later in the interview, the interviewer could skip questions allowing for a more naturally flowing conversation. Interviewers did not take notes and gently guided the conversation which took place in the participants homes. Being in their own environment and the interviewer engaging in building rapport through techniques such as active listening and showing genuine empathy, allowed participants to feel at ease and respond openly and honestly to the questions. This aided the richness of and level of detail in the interviews. The themes reported above and the insights generated were only possible because of the richness of these interview data.

One limitation of this research is that it did not include interviews with CWE themselves, in terms of their experience of ESNs, a gap in the research base also previously identified (Eklund & Sivberg 2003; Harden et al., 2016). It would be of benefit to future research if children's views were considered. Another limitation, for reasons of authority to consent, was that we were unable to invite carers of looked-after CWE to participate in the study. One of our areas stood out as having a very high incidence of looked-after children (see Chapter 3, Figure 3.2). Clearly the circumstances affecting looked after children mean that their experiences will differ from those CWE

whose parents and carers took part in this study. More specifically targeted research is therefore needed to examine the experiences of staff caring for this vulnerable population of CWE with complex needs, and the role ESNs might play in this care. Additionally, due to lack of language resources and translation services, we were unable to invite non-English speakers to participate in the interviews. This excluded a number of potential participants from one area where there were high numbers of non-English speakers. Again, more targeted research is needed to examine the experiences of minority populations, especially in areas where there is a high population of service users from different cultures and ethnic backgrounds. There is a clear need for inclusion of underrepresented populations to establish their views and needs and to evaluate their experience of paediatric epilepsy service provision.

Chapter Seven: General Discussion

7.1 Summary of findings: Questionnaire and interview study

This thesis examined the contribution of paediatric ESNs to paediatric epilepsy services from the carer perspective. This was done by comparing areas with and without a nurse to establish whether there were any significant differences in carer needs and their experience of the service, using both quantitative questionnaire measures and qualitative interview data. In planning the research, we expected greater questionnaire returns, specifically from non-ESN areas, but fewer participants willing to conduct an in-depth interview. However, although questionnaire returns were disappointing from non-ESN areas, a larger than expected number of interview consents were obtained, meaning that out of 58 interviews conducted, 51 of those participants had also returned a questionnaire. Given this overlap, we were able to form hypotheses and gain potential insights concerning our quantitative results from our qualitative research, as discussed in section 7.2 below.

Our quantitative and qualitative data indicate that service models that include a paediatric ESN generate higher levels of carer satisfaction. In the questionnaire study we found overall satisfaction with services to be high across all areas, which is consistent with earlier findings from adult and paediatric settings (Austin et al., 2007; Austin et al., 2015; Higgins et al., 2018; Williams et al., 2018). However, there was significantly greater satisfaction, with a small effect size, in ESN relative to non-ESN areas (see chapter 4, Figure 4.1). Our study was also the first to demonstrate a difference in accessibility scores between ESN and non-ESN areas, with a moderate effect size difference in favour of ESN areas (see chapter 4, Figure 4.1). As we predicted, responses to the remaining needs for information and support subsection of the PRPCS remained high overall as well as highly variable (see chapter 4, Figure 4.1),

with no predictive value in terms of whether an ESN was present. We consider this finding further in section 7.2.1 below.

Our thematic analysis of interview data converged on four main themes, in terms of different types of needs that carers have, and the level to which these are met by their interactions with epilepsy services, including ESNs, where they exist. The themes identified in the analysis were needs for *understanding the condition*, *condition management support*, *educational liaison support*, and *emotional support*. The details of experiences subsumed under these themes inform hypotheses as to the reasons for the pattern of results obtained in the questionnaire study, as discussed in section 7.2 below. To summarise differences between ESN and non-ESN areas in terms of these themes, the greatest differences were found in the latter 3 themes with ESN areas perceived as providing holistic and pro-active support, compared to more variable and ad hoc arrangements found in non-ESN areas. What also became apparent was the variety and extent of problem-solving engaged in by ESNs, from facilitating participation in school trips to managing adverse drug events (chapter 6, sections 6.2 & 6.3). The implications of these findings for appropriate outcome measures in ESN evaluation research are discussed further in section 7.3 below.

7.2 Correspondence between results of questionnaire and interview studies

7.2.1 High levels of remaining needs in both ESN and non-ESN areas

There are many issues that can impact parents/carers as a CWE grows and develops (Austin & Caplan, 2007; Jones et al, 2019). There are also a variety of problems that arise as they grow and develop; children start to attend nursery and school, are outside of the home more and therefore not solely in the care of the primary caregiver (Austin et al., 1998) as they begin sporting pursuits and other extra-curricular activities (Capovilla et al., 2016) and as they grow to an age of wanting more

independence and spending time with friends e.g. sleepovers (Moffat et al., 2009). The presentation of epilepsy can change over time and with development, e.g. puberty (Sheth, 2002), and issues can arise as children start to self-manage more and take a more active role in administering medication (Smith et al., 2018). Changes that occur due to normal growth and development, e.g. height and weight, can also affect medication as well as time spent on particular AEDs and loss of efficacy. These issues were evident in the interview data and go some way to explaining the results of the questionnaire data.

It is understandable that parent/carer needs would remain high as parents adjust and adapt to the changes in their child's epilepsy. Many parents report needing ongoing support to navigate the changes and new challenges in their child's condition.

7.2.2 Satisfaction with services

Levels of overall satisfaction with services was found to be high across all areas in both studies, with a significantly greater satisfaction in ESNs areas within the questionnaire study. The interview data gave further insights into these differences. Firstly, there was reference in regards to the proactive vs ad hoc nature of the support given in ESN vs no-ESN areas. Areas with an ESN experienced high quality, pre-emptive support which was experienced as accessible.

In contrast, parents/carers in services without an ESN reported experiencing difficulties contacting the service or receiving a timely response. Through the ad hoc nature of support, it was highlighted that in the absence of an ESN, other professionals within the service would attempt to fill the void. Although in the quantitative analysis the areas were separated in terms of ESN and no-ESN support, analysis of the qualitative interviews revealed how blurred these boundaries were. Not all services with ESNs are experienced the same and similarly, areas without an ESN have varying levels

of support. Notably, one paediatrician was described as advising parents what time they were at their desk before clinic if parents needed to speak to them between appointments (see chapter 6.2). Conversely, parents also described the difficulties of having to go through the GP for a referral each time support managing the condition was required. These examples illustrate how the qualitative data aids understanding of causes underlying differences in satisfaction scores.

7.2.3 Accessibility

The questionnaire data showed greater differences is accessibility scores with a moderate effect size reported. The qualitative data clearly reflects this. Parents/carers in areas with an ESN described many instances of experiencing an accessible service and shared their positive experiences throughout the interviews (see chapter 6.2 & 6.4). In contrast, parents/carers in areas without an ESN reported experiencing difficulties in contacting the service, because they did not have a phone number, and/or they had to wait longer to receive a response. In some instances, parents would have to wait for a new referral despite being under the care of a consultant.

There was however, variability with accessibility. As previously mentioned, one paediatrician in a no-ESN area provided for parent/carers contacting them directly out of hours if needed (see chapter 6.2).

Overall, our studies showed that services with ESNs are experienced as more accessible as they proactively seek to support parents/carers. In contrast, services without ESN support are experienced as providing parents/carers with support on an ad hoc basis balanced against other workload responsibilities.

7.2.4 Reflections on the value of a mixed-methods approach

The value of a mixed-method approach to health research, previously advocated by the likes of Bishop (2015), is evident in the complementarity of the findings from

each of our studies. Without the qualitative data, we would not have had insight into why the effect sizes were not as large as might be expected in terms of satisfaction with services. The analysis of the interview data provided much greater insight and depth of understanding of the questionnaire results than would have been possible from the questionnaire results alone. Further, the flexibility of qualitative approaches allows the researcher to be responsive to a much wider range of issues than might be admitted by a more quantitative measure (Dures et al., 2010). Future studies of patient experiences of health services would benefit from integrating interpretations of specific questionnaire responses with more qualitative accounts of patient/carer experiences of services. Such an approach could occur within the pragmatic framework outlined by Bishop (2015), in which the epistemological stance taken within the research design is acknowledged. To continue to improve the value of service evaluation measures, it is essential to know why people answer or give ratings in the way they do, and what subjective experiences inform their overall perceptions and evaluations of services.

7.3 Outcome measures in ESN evaluation research

RCTs are treated as the gold standard in health research (Bothwell et al., 2016). However, there has been some discussion of the limitations of the RCT methodology in both medicine (e.g. Kostis & Dobrzynski, 2020) and mental health research (e.g. Rosenkranz et al., 2019). A neglected area of discussion has been on appropriate outcome measures for roles such as that of specialist nurses (Campbell et al., 2019). Campbell and colleagues (2019) highlight some of these limitations which include the time restrictions of assessments, which they suggest may not allow for the ESN role to become fully established. There are some RCT studies in the field of adult ESNs, with a variety of outcome measures (such as seizure frequency, depression, etc.). Although differences have been found in satisfaction, there have not been any observed

differences in these types of clinical measures. The lack of suitable measures needs to be addressed (see suggestions below, in section 7.5). As Campbell et al. (2019) clarify, the presence of ESNs tends to signify a model of teamwork and care that means differences between ESN and non-ESN services go beyond the presence of the ESN. However, there is difficulty of capturing these differences. Our qualitative findings illustrate the variety of problems for which ESNs are contacted and the variety even within each type of ESN setting (adult, paediatric, tertiary etc.), so single clinical outcomes would be inadequate measures in this case. Assessments of whether interventions were timely, and solutions optimal, would be more appropriate. As discussed, even summary measures of satisfaction with services may not capture differences between service delivery models adequately.

7.4 Broadening definitions of emotional support functions

In chapter six, although we distinguished between different types of support needed by parents/carers of CWE, these themes were interlinked, e.g., having contact with a person with good knowledge of the child's condition to liaise with a school or other service removed stress and an emotional burden from, and thereby also served as a form of emotional support. Equally, informational support reduced the emotional burden on parents/carers through alleviating uncertainty, lending to feelings of empowerment, increased confidence, and autonomy in managing their child's epilepsy. Similarly, emotional support was not experienced as purely help in managing emotional responses in times of distress, but rather as easing the emotional burden of caring for a child with epilepsy in many areas by meeting identified needs for information, condition management and liaison with others. Similar needs were highlighted by Harden et al. (2016) who noted the emotional burden of living with epilepsy was more prominent in the concerns of parents of CWE requiring continuing support from

professionals (McNelis et al., 2007). Overall, the value of the emotional support provided by ESNs lies in the holistic approach that an ESN provides for, mirroring the complex and interconnected needs of families of CWE.

7.5 Recommendations for further research

The results of these studies have clear implications for future research. Our study (Beesley et al., 2021) was the first to directly compare areas with and without paediatric ESN provision. As identified by Campbell et al (2019), there is a need for more research using a range of methodologies in this area to better assess the gaps in paediatric ESN research, and to build a reliable evidence base.

Carers of looked-after CWE were not able to participate in either study due to issues of consent. This issue was highlighted by the fact that one of the areas in the study had a very high incidence of looked-after children with epilepsy (see Chapter 3, Figure 3.2). The exclusion of this population and their experiences from this research highlights the need for future research specifically aimed at examining the experiences of carers and staff supporting this vulnerable population of CWE, and the role ESNs might play in their care. Support may be particularly necessary for this group, especially for those looked-after CWE with complex needs and co-morbidities. It would be interesting to conduct interviews with carers of looked-after CWE to establish whether emotional support is valued in the same way, or if more practical aspects of the ESNs work are highlighted and, if so, what aspects are experienced as the most valuable. Similarly, we were unable to include more complex cases where CWE were under a tertiary level neurologist. The work of an ESN in a tertiary setting with the most difficult cases may vary from our research in secondary settings, e.g. paediatricians with special interest in epilepsy caseloads, and should be examined.

Due to a lack of language resources and translation services, we were unable to invite non-English speakers to participate in the interview study. Consequently, a number of participants were excluded from one area where there were high number of non-English speaking parents/carers of CWE (Area 1, see chapter 3, Figure 3.2). They were, however, able to take part in the questionnaire study. Questionnaires were sent out to the participants' homes and they were able to translate anything they did not understand in the same way they would for any clinic letters or other correspondence, e.g., verbal translation by an English-speaking family member or friend, or by translation apps such as Google translate. To ensure that we have a full appreciation of all the factors affecting experiences of paediatric epilepsy care, it is imperative that future research examines the experiences of ethnic minority populations, especially in areas where there is a high population of service users from different ethnic backgrounds. There is a clear need for inclusion of underrepresented populations to establish their views, needs and to evaluate their experience of epilepsy services.

In both studies we examined the needs and experiences of parents of CWE, however, the views of CWE themselves were not directly investigated. Again, there is a clear need for studies that focus on the views of children and adolescents (e.g., McEwan et al., 2004). If these studies were to be repeated, it would be valuable to understand their needs, understandings, expectations, and experiences of epilepsy services and their experiences of the role of the ESN.

Another area that would benefit from further research is the contribution of paediatric ESNs in the transition of young people with epilepsy to adult services and the needs and experiences of service users during the transition period. There is very little research that specifically assesses the contribution of paediatric ESNs in the transition to adult services (Camfield et al., 2019) and there is a lack of transition

plans/programmes (Goselink et al., 2022). The interview study only briefly touched upon this topic with parents of CWE owing to a lack of young people in the appropriate age range. However, it would be worth examining this area in more detail with a specific focus on paediatric ESNs. This area was lacking from our research in an otherwise comprehensive study of ESNs.

Finally, due to the limitations of RTCs in the assessment of ESNs (Campbell et al., 2019), studies in which carer report is supplemented by audit of service contacts, for example, call logs and other records, are needed to establish the frequency of efforts to contact services between clinics, and to provide confirmatory reports of the types of presenting issues and their resolution. More suitable outcome measures are needed to assess the variety of tasks and problem solving ESNs engage in. Integrated with interview data that reviews specific examples and outcomes, such research would provide a better understanding of the emergent needs of parents/carers and their experience of epilepsy services. Expert researchers judging whether a response was timely and solution optimal to communications from carers may be good outcome measures in future research. Although our study provides an overall picture of carers' experience with services over time, this approach would give a more specific and detailed perspective of more recent encounters and allow examination of what the service is currently doing well and where improvements could be made.

7.6 Conclusions

Our data suggest that from the perspective of parents/carers of CWE, ESNs are successfully fulfilling their roles of being an expert resource, an accessible point of contact, a liaison with and trainer of other services, and an essential source of support for carers (NICE, 2004). Fulfilling this role not only mitigates the burden on carers and supports CWE accessing education services, but it also relieves pressure on other

clinicians within epilepsy services (NICE, 2004). In services that lack ESNs, other team members are attempting to fill voids beyond the boundaries of their roles, or conversely, patient communications are not being addressed in a timely manner. Our mixed methods approach allowed us to understand some of the experiences underpinning questionnaire responses in terms of service satisfaction, as well as suggesting the wide range of issues addressed by ESNs. This suggests that future research evaluating ESNs must address this diversity of issues when devising appropriate outcome measures.

References

Aguiar, B. V., Guerreiro, M.M., McBrian, D., & Montenegro, M.A. (2007). Seizure impact on the school attendance in children with epilepsy. *Seizure, 16*(8), 698-702. https://doi.org/10.1016/j.seizure.2007.05.013

Alwash, R.H., Hussein, M.J., & Matloub, F.F. (2000). Symptoms of anxiety and depression among adolescents with seizures in Irbid, Northern Jordan. *Seizure, 9*(6), 412-416. https://doi.org/10.1053/seiz.2000.0427

American Psychiatric Association. (2013). *Diagnostic and statistical manual* (5th Ed.). Arlington, VA: Author.

Andelman, F. (2000). Analysis of quality of life among adolescents with epilepsy. *International Journal of Adolescent Mental Health, 12*(1), S17-24. https://doi.org/10.1515/IJAMH.2000.12.S1.17

Anderson, G.D. (2002). Children versus adults: Pharmacokinetic and adverse-effect differences. *Epilepsia, 43*(s3), 53-59. https://doi.org/10.1046/j.1528-1157.43.s.3.5.x

Anderson, P. (2002). Assessment and development of executive function (EF) during childhood. *Child neuropsychology, 8*(2), 71-82. https://doi.org/10.1076/chin.8.2.71.8724

Appleton, R. E., & Sweeney, A. (1995). The management of epilepsy in children: the role of the clinical nurse specialist. *Seizure*, *4*(4), 287-291. https://doi.org/10.1016/S1059-1311(95)80006-9

Arunkumar, G., Wyllie, E., Kotagal, P., Ong, H.T., & Gilliam, F. (2000). Parent- and patient- validated content for pediatric epilepsy quality of life assessment. *Epilepsia, 41*(11), 1474-1484. https://doi.org/10.1111/j.1528-1157.2000.tb00125.x

Austin, J.K. (1988). Childhood epilepsy: Child adaptation and family resources. *Journal of child and adolescent psychiatric mental health nursing, 1*(1), 18-24. https://doi.org/10.1111/j.1744-6171.1988.tb00222.x

Austin, J. K., & Caplan, R. (2007). Behavioral and psychiatric comorbidities in pediatric epilepsy: toward an integrative model. *Epilepsia*, *48*(9), 1639-1651. https://doi.org/10.1111/j.1528-1167.2007.01154.x

Austin, J.K., Dunn, D.W., Caffrey, H.M., Perkins, S.M., Harezlak, J., & Rose, D.F. (2002). Recurrent seizure and behaviour problems in children with first recognized seizures: A prospective study. *Epilepsia, 43*(12), 1564-1573. https://doi.org/10.1046/j.1528-1157.2002.26002.x

Austin, J.K., Dunn, D.W., & Huster, G.A. (2000). Childhood epilepsy and asthma: Changes in behaviour problems related to gender and change in condition severity. *Epilepsia, 41*(5), 615-623. https://doi.org/10.1111/j.1528-1157.2000.tb00217.x

Austin, J.K., Dunn, D.W., Johnson, C.S., & Perkins, S.M. (2004). Behavioral issues involving children and adolescents with epilepsy and the impact to their families: recent research data. *Epilepsy & Behavior, 5*(s3), 33-41. https://doi.org/10.1016/j.yebeh.2004.06.014

Austin, J.K., Harezlak, J., Dunn, D.W., Huster, G.A., Rose, D.F., & Ambrosius, W.T. (2001). Behavior problems in children before first recognized seizures. *Pediatrics, 107*(1), 115-122. https://doi.org/10.1542/peds.107.1.115

Austin, J.K., Huberty, T.J., Huster, G.A., & Dunn, D.W. (1999). Does academic achievement in children with epilepsy change over time? *Developmental medicine & child neurology, 41*(7), 473-479. https://doi.org/10.1111/j.1469-8749.1999.tb00640.x

Austin, J.K., Huberty, T.J., Huster, G.A., & Dunn, D.W. (1998). Academic achievement in children with epilepsy or asthma. *Developmental medicine & child neurology, 40*(4)*,* 248-255. https://doi.org/10.1111/j.1469-8749.1998.tb15457.x

Austin, J.K., Huster, G.A., Dunn, D.W., & Risinger, M.W. (1996). Adolescents with active or inactive epilepsy or asthma: A comparison of quality of life. *Epilepsia, 37*(12)*,* 1228-1238. https://doi.org/10.1111/j.1528-1157.1996.tb00558.x

Austin, J.K., Perkins, S.M., Johnson, C.S., Fastenau, P.S., Byars, A.W., deGrauw, T.J., & Dunn, D.W. (2010). Self-esteem and symptoms of depression in children with seizures: Relationships and neuropsychological functioning and family variables over time. *Epilepsia, 51*(10)*,* 2074-2083. https://doi.org/10.1111/j.1528-1167.2010.02575.x

Austin, J.K., Perkins, S.M., Johnson, C.S., Fastenau, P.S., Byars, A.W., deGrauw, T.J., & Dunn, D.W. (2011). Behavior problems in children at time of first recognized seizure and changes over the following 3 years. *Epilepsy & Behavior, 21*(4), 373-381. https://doi.org/10.1016/j.yebeh.2011.05.028

Austin, J.K., Risinger, M.W., & Beckett, L.A. (1992). Correlates of behaviour problems in children with epilepsy. *Epilepsia, 33*(6), 1115-1122. https://doi.org/10.1111/j.1528-1157.1992.tb01768.x

Austin, J.K., Shafer, P.O., & Deering, J.B. (2002). Epilepsy familiarity, knowledge, and perceptions of stigma: report from a survey of adolescents in the general population. *Epilepsy & Behavior, 3*(4), 368-375. https://doi.org/10.1016/S1525-5050(02)00042-2

Aydin, K., & Yildiz, H. (2007). Teachers' perceptions in central Turkey concerning epilepsy and asthma and the short-term effect of brief education on the perception of epilepsy. *Epilepsy & Behavior, 10*(2), 286-290. https://doi.org/10.1016/j.yebeh.2006.09.012

Baker, G.A., Spector, S., McGrath, Y., & Soteriou, H. (2005). Impact of epilepsy in adolescence: A UK controlled study. *Epilepsy & Behavior, 6*(4), 556-562. https://doi.org/10.1016/j.yebeh.2005.03.011

Baki, O., Erdogan, A., Kantarci, O., Akisik, G., Kayaalp, L., & Yalcinkaya, C. (2004). Anxiety and depression in children with epilepsy and their mothers. *Epilepsy & Behavior, 5,* 958-964. https://doi.org/10.1016/j.yebeh.2004.08.016

Baum, K.T., Byars, A.W., deGrauw, T.J., Dunn, D.W., Bates, J.E., Howe, S.R., Chiu, C.Y.P., & Austin, J.K. (2010). The effect of temperament and neuropsychological functioning on behaviour problems in children with new-onset seizures. *Epilepsy & Behavior, 17*(4), 467-473. https://doi.org/10.1016/j.yebeh.2010.01.010

Baumrind, D. (1971). Current patterns of parental authority. *Developmental psychology monographs, 4*(1), 1-103. https://doi.org/10.1037/h0030372

Beesley, R. E., Walton, C., Hindley, D., Jameson, H., Panwar, N., & Lew, A. R. (2021). Carer evaluations of paediatric epilepsy services with and without epilepsy specialist nurse provision. *Seizure*, *91*, 174-180. https://doi.org/10.1016/j.seizure.2021.06.012

Beesley, R. E., Lew, A. R., Hindley, D., Jameson, H., Panwar, N., & Walton, C. (2022). Carer's perceptions of paediatric epilepsy services with and without epilepsy specialist nurses: A thematic analysis. *Seizure*, *103*, 26-31. https://doi.org/10.1016/j.seizure.2022.10.010

Behrouzian, F., & Neamatpour, S. (2010). Parental knowledge and mental health in parents of children with epilepsy. *Pakistan Journal of Medical Sciences, 26*(1), 191-194.

Berg, A.T., Kaiser, K., Dixon-Salazar, T., Elliot, A., McNamara, N., Meskis, M.A., … Rozek, C. (2019). Seizure burden in severe early-life epilepsy: Perspectives from parents. *Epilepsia Open, 2,* 293-301. https://doi.org/10.1002/epi4.12319

Berg, A.T., Langfitt, J.T., Testa, F.M., Levy, S.R., DiMario, F., Westerveld, M., & Kulas, J. (2007). Global cognitive function in children with epilepsy: A community-based study. *Epilepsia, 49,* 608-614. https://doi.org/10.1111/j.1528-1157.1995.tb01006.x

Berg, A.T., Shinnar, S., Shapiro, E.D., Salomon, M.E., Crain, E.F., & Hauser, W.A. (1995). Risk factors for a first febrile seizure: A matched case-control study. *Epilepsia, 36,* 334-341. https://doi.org/10.1111/j.1528-1157.1995.tb01006.x

Besag, F.M.C., Nomayo, A., & Pool, F. (2005). The reactions of parents who think that a child is dying in a seizure- In their own words. *Epilepsy & Behavior, 7,* 517-523. https://doi.org/10.1016/j.yebeh.2005.07.015

Bishop, F. L. (2015). Using mixed methods research designs in health psychology: An illustrated discussion from a pragmatist perspective. *British journal of health psychology*, *20*(1), 5-20. https://doi.org/10.1111/bjhp.12122

Bishop, M., & Boag, E.M. (2006). Teachers' knowledge about epilepsy and attitudes toward students with epilepsy: Results of a national survey. *Epilepsy & Behavior, 8,* 397-405. https://doi.org/10.1016/j.yebeh.2005.11.008

Blake, R. V., Wroe, S. J., Breen, E. K., & McCarthy, R. A. (2000). Accelerated forgetting in patients with epilepsy: evidence for an impairment in memory consolidation. *Brain*, *123*(3), 472-483. https://doi.org/10.1093/brain/123.3.472

Bourgeois, B.F. (2004). Determining the effects of antiepileptic drugs on cognitive function in pediatric patients with epilepsy. *Journal of child neurology, 19,* S15-S24. https://doi.org/10.1177/088307380401900103

Bompori, E., Niakas, D., Nakou, I., Siamopoulou-Mavridou, A., & Tzoufi, M.S. (2014). Comparative study of the health-related quality of life of children with epilepsy and their parents. *Epilepsy & Behavior, 41,* 11-17. https://doi.org/10.1016/j.yebeh.2014.09.009

Bothwell, L. E., Greene, J. A., Podolsky, S. H., & Jones, D. S. (2016). Assessing the gold standard—lessons from the history of RCTs. *New England Journal of Medicine, 374*(22), 2175-2181. https://doi.org/10.1056/NEJMms1604593

Braun, K. (2017). Preventing cognitive impairment in children with epilepsy. *Current opinion in neurology, 30,* 140-147. https://doi.org/10.1097/WCO.0000000000000424

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners.* Sage Publications, Thousand Oaks.

Brobeck, E., Bergh, H., Odencrants, S., & Hildingh, C. (2011). Primary healthcare nurses' experiences with motivational interviewing in health promotion practice. *Journal of clinical nursing*, *20*(23-24), 3. https://doi.org/10.1111/j.1365-2702.2011.03874.x

Brown, B. (2006). Shame resilience theory: A grounded theory study on women and shame. *Families in society: The journal of contemporary social services, 87,* 43-52. https://doi.org/10.1606/1044-3894.3483

Brna, P.M., Gordon, K.E., Woolridge, E., Dooley, J.M., & Wood, E. (2017). Perceived need for restrictions on activity for children with epilepsy. *Epilepsy & Behavior, 73,* 236-239. https://doi.org/10.1016/j.yebeh.2017.05.012

Buelow, J.M. (2007). An intervention for parents of children with epilepsy and significant learning problems: lessons learned from the feasibility study. *Journal of the American Psychiatric Nurses Association, 13,* 146-153. https://doi.org/10.1177/1078390307303747

Buelow, J.M., Austin, J.K., Perkins, S.M., Shen, J., Dunn, D.W., & Fastenau, P.S. (2003). Behavior and mental health problems in children with epilepsy and low IQ. *Developmental Medicine and Child Neurology, 45,* 683-692. https://doi.org/10.1017/S0012162203001270

Buelow, J.M., McNelis, A., Shore, C.P., & Austin, J.K. (2006). Stressors of parents of children with epilepsy and intellectual disability. *Journal of Neuroscience Nursing, 38,* 147–154, 176. https://doi.org/10.1097/01376517-200606000-00003

Butler, C. R., & Zeman, A. Z. (2008). Recent insights into the impairment of memory in epilepsy: transient epileptic amnesia, accelerated long-term forgetting and remote memory impairment. *Brain*, *131*(9), 2243-2263. https://doi.org/10.1093/brain/awn127

Camfield, C., Breau, L., & Camfield, P. (2001). Impact of pediatric epilepsy on the family: A new scale for clinical and research use. *Epilepsia, 42,* 104-112. https://doi.org/10.1046/j.1528-1157.2001.081420.x

Campbell, F., Sworn, K., Booth, A., Reuber, M., Grunewald, R., Mack, C., & Dickson, J. (2019). Epilepsy specialist nurses the evidence (ESPENTE): a systematic mapping review.

Caplan, R., Siddarth, P., Gurbani, S., Hanson, R., Sankar, R., & Shields, W.D. (2005). Depression and anxiety disorders in pediatric epilepsy. *Epilepsia, 46,* 720-730. https://doi.org/10.1111/j.1528-1167.2005.43604.x

Caplan, R., Siddarth, P., Gurbani, S., Ott, D., Sankar, R., & Shields, W. (2004). Psychopathology and pediatric complex partial seizures: seizure-related, cognitive, and linguistic variables. *Epilepsia, 45,* 1273-1281. https://doi.org/10.1111/j.0013-9580.2004.58703.x

Capovilla, G., Kaufman, K.R., Perucca, E., Moshe, S.L., & Arida, R.M. (2016). Epilepsy, seizures, physical exercise, and sports: A report from the ILAE Task Force on sports and epilepsy. *Epilepsia, 57,* 6-12. https://doi.org/10.1111/epi.13261

Carrizosa, J., An, I., Appleton, R., Camfield, P., & Von Moers, A. (2014). Models for transition clinics. *Epilepsia*, *55*, 46-51. https://doi.org/10.1111/epi.12716

Carlson, G., & Cantwell, D. (1980). Unmasking masked depression in children and adolescents. *American Journal of Psychiatry, 137,* 445-449. https://doi.org/10.1176/ajp.137.4.445

Carlton-Ford, S., Miller, R., Brown, M., Nealeigh, N., & Jennings, P. (1995). Epilepsy and children's social and psychological adjustment. *Journal of Health & Social Behavior, 36,* 285–301. https://doi.org/10.2307/2137344

Carlton-Ford, S., Miller, R., Nealeigh, N., & Sanchez, N. (1997). The effect of perceived stigma and the psychological over-control on the behavioural problems of children with epilepsy. *Seizure, 6,* 383-391. https://doi.org/10.1016/S1059-1311(97)80038-6

Carpay, H.A., Vermeulen, J., Stroink, H., Brouwer, O.F., Peters, A.C., van Donselaar, C., Aldenkamp, A., & Arts, W. (1997). Disability due to restrictions in childhood epilepsy. *Developmental Medicine & Child Neurology, 39,* 521-526. https://doi.org/10.1111/j.1469-8749.1997.tb07480.x

Carter, B., Cook, G., Bray, L., Collingwood, A., Saron, H., & Rouncefield-Swales, A. (2022). Parents'/caregivers' fears and concerns about their child's epilepsy: A scoping review. *Plos one*, *17*(9), e0274001. https://doi.org/10.1371/journal.pone.0274001

Cianchetti, C., Bianchi, E., Guerrini, R., Baglietto, M.G., Briguglio, M., Cappelletti, S., … TASCA study group. (2018). Symptoms of anxiety and depression and family's quality of life in children and adolescents with epilepsy. *Epilepsy & Behavior, 79,* 146-153. https://doi.org/10.1016/j.yebeh.2017.11.030

Cianchetti, C., Messina, P., Pupillo, E., Crichiutti, G., Baglietto, M.G., Veggiotti, P., … Beghi, E. (2015). The perceived burden of epilepsy: Impact on the quality of life of children and adolescents and their families. *Seizure, 24,* 93-101. https://doi.org/10.1016/j.seizure.2014.09.003

Cianchetti, C., Messina, P., Pupillo, E., Crichiutti, G., Baglietto, M.G., Veggiotti, P., … TASCA study group. (2014). The perceived abundance of epilepsy: Impact on the quality of life of children and adolescents and their families. *Seizure, 24,* 93-101. https://doi.org/10.1016/j.seizure.2014.09.003

Chapieski, L., Brewer, V., Evankovich, K., Culhane-Shelburne, K., Zelman, K., & Alexander, A. (2005). Adaptive functioning in children with seizures: Impact of maternal anxiety about epilepsy. *Epilepsy & Behavior, 7,* 246-252. https://doi.org/10.1016/j.yebeh.2005.05.002

Chen, H., Cohen, P. & Chen, S. (2010). How big is a big odds ratio? Interpreting the magnitudes of odds ratios in epidemiological studies. *Communications in Statistics-Simulation and Computation, 39(4),* 860-864. https://doi.org/10.1080/03610911003650383

Chew, J., Carpenter, J., & Haase, A. M. (2017). Young people's experiences of epilepsy: a scoping review of qualitative studies. *Health & social work*, *42*(3), 167-176. https://doi.org/10.1093/hsw/hlx020

Chiesa, V., Gardella, E., Tassi, L., Canger, R., Lo Russo, G., Piazzini, A., … Canevini, M.P. (2007). Age-related gender differences in reporting ictal fear: analysis of case histories and review of the literature. *Epilepsia, 48,* 2361-2364. https://doi.org/10.1111/j.1528-1167.2007.01227.x

Chinthapalli, R., Serane, V. T., Pill, J., Millard, D., Batten, D., & Chinthapalli, V. K. (2008). Epilepsy clinic services, nice guidelines and patient satisfaction—An audit. *Seizure*, *17*(7), 611-616. https://doi.org/10.1016/j.seizure.2008.03.003

Chiou, H., & Hsieh, L. (2008). Parenting stress in parents of children with epilepsy and asthma. *Journal of child neurology, 23,* 301-306. https://doi.org/10.1177/0883073807308712

Chong, L., Jamieson, N.J., Gill, D., Singh-Grewal, D., Craig, J.C., Ju, A., … Tong, A. (2016). Children's experiences of epilepsy: A systematic review of qualitative studies. *Pediatrics, 138.* https://doi.org/10.1542/peds.2016-0658.

Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The psychologist*, *26*(2).

Clarke, V., & Braun, V. (2017). Thematic analysis. *The journal of positive psychology*, *12*(3), 297-298. https://doi.org/10.1080/17439760.2016.1262613

Cohen, N.J., Davine, M., Horodezky, N., Lipsett, L., & Isaacson, L. (1993). Unsuspected language impairment in psychiatrically disturbed children: prevalence and language and behavioural characteristics. *Journal of the American Academy of Child and Adolescent Psychiatry, 32,* 595-603. https://doi.org/10.1097/00004583-199305000-00016

Collins, S. (2005). Explanations in consultations: the combined effectiveness of doctors' and nurses' communication with patients. *Medical education*, *39*(8), 785-796. https://doi.org/10.1111/j.1365-2929.2005.02222.x

Conant, K.D., Morgan, A.K., Muzykewicz, D., Clark, D.C., & Thiele, E.A. (2008). A karate program for improving self-concept and quality of life in childhood epilepsy: Results of a pilot study. *Epilepsy & Behavior, 12,* 61-65. https://doi.org/10.1016/j.yebeh.2007.08.011

Conant, L.L., Wilfong, A., Inglese, C., & Schwarte, A. (2010). Dysfunction of executive and related processes in childhood absence epilepsy. *Epilepsy & Behavior, 18,* 414-423. https://doi.org/10.1016/j.yebeh.2010.05.010

Cook, G., Bray, L., Carter, B., Gringras, P., Morris, C., Pal, D. K., ... & Wiggs, L. (2023). A cross-sectional survey of healthcare professionals supporting children and young people with epilepsy and their parents/carers: which topics are raised in clinical consultations and can healthcare professionals provide the support needed?. *Epilepsy & Behavior*, *149*, 109543. https://doi.org/10.1016/j.yebeh.2023.109543

Cottrell, L., & Khan, A. (2005). Impact of Childhood Epilepsy on Maternal Sleep and Socioemotional Functioning. *Clinical Pediatrics, 44(7),* 613–616. https://doi.org/10.1177/000992280504400709

Cushner-Weinstein, S., Berl, M., Salpekar, J.A., Johnson, J.L., Pearl, P.L., Conry, J.A., … Weinstein, S.L. (2006). The benefits of a camp designed for children with epilepsy: Evaluating adaptive behaviors over 3 years. *Epilepsy & Behavior, 10,* 170-178. https://doi.org/10.1016/j.yebeh.2006.10.007

Davies, S., Heyman, I., & Goodman, R. (2003). A population survey of mental health problems in children with epilepsy. *Developmental Medicine & Child Neurology, 45,* 292-295. https://doi.org/10.1017/S0012162203000550

De Boer, H.M. (2002). "Out of the shadows": A global campaign against epilepsy. *Epilepsia, 43,* 7-8. https://doi.org/10.1046/j.1528-1157.43.s.6.4.x

De Boer, H.M., Mula, M., & Sander, J.W. (2008). The global burden and stigma of epilepsy. *Epilepsy & Behavior, 12,* 540-546. https://doi.org/10.1016/j.yebeh.2007.12.019

De Silva, A., & Valentine, N. (2000). A framework for measuring responsiveness. Global Programme on Evidence for Health Policy Discussion Paper. No. 32. *World Health Organization, Geneva*.

Devinsky, O., Westbrook, L., Cramer, J., Glassman, M., Perrine, K., & Camfield, C. (1999). Risk factors for poor health-related quality of life in adolescents with epilepsy. *Epilepsia, 40,* 1715-1720. https://doi.org/10.1111/j.1528-1157.1999.tb01588.x

Dodson, W. (2001). Epilepsy, cerebral palsy, and IQ. In J., Pellock, W.E., Dodson, B., Bourgeois, (Eds) p. 613-627. *Pediatric Epilepsy Diagnosis and Therapy*. New York: Demos Medical Publishing.

Dorris, L., Broome, H., Wilson, M., Grant, C., Young, D., Baker, G., ... & Wright, I. (2017). A randomized controlled trial of a manual-based psychosocial group intervention for young people with epilepsy [PIE]. *Epilepsy & Behavior*, *72*, 89-98. https://doi.org/10.1016/j.yebeh.2017.04.007

Duffy, L. V. (2011). Parental coping and childhood epilepsy: the need for future research. *Journal of Neuroscience Nursing*, *43*(1), 29-35. https://doi.org/10.1097/JNN.0b013e3182029846

Dunn, D.W., & Austin, J.K. (1999). Behavior issues in pediatric epilepsy. *Neurology, 53,* 96-100.

Dunn, D.W., Austin, J.K., & Huster, G.A. (1999). Symptoms of depression in adolescents with epilepsy. *Journal of the American Academy of child and adolescent psychiatry, 38,* 1132-1138. https://doi.org/10.1097/00004583-199909000-00017

Dunn, D.W., Johnson, C.S., Perkins, S.M., Fastenau, P.S., Byars, A.W., deGrauw, T.J., & Austin, J.K. (2010). Academic problems in children with seizures: Relationships with neuropsychological functioning and family variables during the first 3 years after onset. *Epilepsy & Behavior, 19,* 455-461. https://doi.org/10.1016/j.yebeh.2010.08.023

Dures, E., Rumsey, N., Morris, M., & Gleeson, K. (2011). Mixed methods in health psychology: Theoretical and practical considerations of the third paradigm. *Journal of health psychology*, *16*(2), 332-341. https://doi.org/10.1177/1359105310377537

Eddy, C.M., Rickards, H.E., & Cavanna, A.E. (2012). Behavioral adverse effects of antiepileptic drugs in epilepsy. *Journal of clinical psychopharmacology, 32,* 362-375. https://doi.org/10.1097/JCP.0b013e318253a186

Edwards, P.J., Roberts, I., Clarke, M.J., Diguiseppi, C., Wentz, R., Kwan, I., Cooper, R., Felix, L.M., & Pratap, S. (2009). Methods to increase response to postal and electronic questionnaires. *Cochrane Database of Systematic Reviews, 3*(3), https://doi.org/10.1002/14651858.MR000008.pub4

Ek Hauge, N. C., Henning, O., Nakken, K. O., & Bjørge, H. (2020). Patient satisfaction with information provided by epilepsy specialist nurses: Results of an online survey. *Epilepsy & behavior, 112*, 107273. https://doi.org/10.1016/j.yebeh.2020.107273

Elliott, A.N., Lach, L., & Smith, M.L. (2005). 'I just want to be normal': a qualitative study of how children and adolescents view the impact of intractable epilepsy on their quality of life. *Epilepsy & Behavior, 7,* 664-678. https://doi.org/10.1016/j.yebeh.2005.07.004

Ellis, N., Upton, D., & Thompson, P. (2000). Epilepsy and the family: a review of current literature. *Seizure, 9,* 22-30. https://doi.org/10.1053/seiz.1999.0353

Eom, S., Caplan, R., & Berg, A.T. (2016). Behavioural problems and childhood epilepsy: Parent vs child perspectives. *Journal of Pediatrics, 179,* 233-239. https://doi.org/10.1016/j.jpeds.2016.08.096

Epilepsy Action. (2009). *Epilepsy in England: time for change.* Retrieved from https://www.epilepsy.org.uk/sites/epilepsy/files/images/campaigns/Epilepsy_in_England_-_Time_for_change_report.pdf

Epilepsy Action. (2010). *Best care: The value of epilepsy specialist nurses.* Retrieved from https://www.epilepsy.org.uk/sites/epilepsy/files/images/campaigns/care-the-value-of-epilepsy-specialist-nurses.pdf

Epilepsy Society. (2019). *Anti-epileptic drugs.* Retrieved from https://www.epilepsysociety.org.uk/antiepileptic-drugs/

Ettinger, A.B., Weibrot, D.M., Nolan, E.E., Gadow, K.D., Vitale, S.A., Andriola, M.R., … & Hermann, B.P. (1998). Symptoms of depression and anxiety in pediatric epilepsy patients. *Epilepsia, 39,* 595-599. https://doi.org/10.1111/j.1528-1157.1998.tb01427.x

Falco-Walter, J.J., Scheffer, I.E., & Fisher, R.S. (2018). The new definition and classification of seizures and epilepsy. *Epilepsy Research, 139,* 73-79. https://doi.org/10.1016/j.eplepsyres.2017.11.015

Fastenau, P.S., Johnson, C.S., Perkins, S.M. et al. (2009). Neuropsychological status at seizure onset in children: risk factors for early cognitive deficits. *Neurology, 73,* 526-534. https://doi.org/10.1212/WNL.0b013e3181b23551

Fayed, N., Davis, A.M., Streiner, D.L., Rosenbaum, P.L., Cunningham, C.E., Lach, L.M., … Ronen, G.M. (2015). Children's perspective of quality of life in epilepsy. *Neurology, 84,* 1830-1837. https://doi.org/10.1212/WNL.000000000000153

Ferrer, P., Ballarin, E., Sabate, M., Vidal, X., Rottenkolber, M., Amelio, J., … Ibanez, L. (2014). Antiepileptic drugs and suicide: A systematic review of adverse effects. *Neuroepidemiology, 42,* 107-120. https://doi.org/10.1159/000356807

Ferro, M. (2014). Risk factors for health-related quality of life in children with epilepsy: A meta-analysis. *Epilepsia, 55,* 1722-1731. https://doi.org/10.1111/epi.12772

Ferro, M.A., Avery, L., Fayad, N., Streiner, D.L., Cunningham, C.E., Boyle, M.H., … Ronen, G.M. (2017). Child and parent reported quality of life trajectories in children with epilepsy: A prospective cohort study. *Epilepsia, 58,* 1277-1286. https://doi.org/10.1111/epi.13774

Ferro, M.A., Avison, W.R., Campbell, M.K., & Speechley, K.N. (2011). Prevalence and trajectories of depressive symptoms in mothers of children with newly diagnosed epilepsy. *Epilepsia, 52*, 326-336. https://doi.org/10.1111/j.1528-1167.2010.02899.x

Ferro, M.A., & Speechley, K.N. (2009). Depressive symptoms among mothers of children with epilepsy; a review of prevalence, associated factors, and impact on children. *Epilepsia, 50,* 2344-2354. https://doi.org/10.1111/j.1528-1167.2009.02276.x

Filippello, P., Sorrenti, L., Larcan, R., & Rizzo, A. (2013). Academic underachievement, self-esteem and self-efficacy in decision making. *Mediterranean journal of clinical psychology, 1,* 1-11. https://doi.org/10.6092/2282-1619/2013.1.934

Fincham, J.E. (2008). Response rates and responsiveness for surveys, standards and the Journal. *American Journal of Pharmaceutical Education, 72*(2), 43. https://doi.org/10.5688/aj720243

Fisher, R.S., Cross, J.H., D'Souza, C., French, J.A., Haut, S.R., Higurashi, N., … & Zuberi, S.M. (2017). Instruction manual for the ILAE 2017 operational classification of seizure types. *Epilepsia, 58,* 531-542. https://doi.org/10.1111/epi.13671

Fisher, R.S., Cross, J.H., French, J.A., Higurashi, N., Hirsch, E., Jansen, F.E., … & Zuberi, S.M. (2017). Operational classification of seizure types by the International League Against Epilepsy: Position paper of the ILAE Commission for Classification and Terminology. *Epilepsia, 58,* 522-530. https://doi.org/10.1111/epi.13670

Flick, U. (1998). *An Introduction to Qualitative Research*. SAGE Publications.

Fowler, S. B., Hauck, M. J., Allport, S., & Dailidonis, R. (2021). Knowledge and fears of parents of children diagnosed with epilepsy. *Journal of Pediatric Nursing*, *60*, 311-313. https://doi.org/10.1016/j.pedn.2021.08.008

Freeman-Jones, E., Wilson, G., Eldred, C., Mercier, A., Hendry, K., Swindler, A., ... & Brunklaus, A. (2024). Caregiver burden and therapeutic needs in Dravet syndrome-A national UK cross-sectional questionnaire study. *European Journal of Paediatric Neurology*, *53*, 138-143. https://doi.org/10.1016/j.ejpn.2024.10.010

Galvin, J., Suominen, E., Morgan, C., O'Connell, E. J., & Smith, A. P. (2015). Mental health nursing students' experiences of stress during training: a thematic analysis of qualitative interviews. *Journal of psychiatric and mental health nursing*, *22*(10), 773-783. https://doi.org/10.1111/jpm.12273

Garner, R.E., Arim, R.G., Kohen, D.E., Lach, L.M., MacKenzie, M.J., Brehaut, J.C., & Rosenbaum, P.L. (2011). Parenting children with neurodevelopmental disorders and/or behaviour problems. *Child: care, health and development, 39,* 412-421. https://doi.org/10.1111/j.1365-2214.2011.01347.x

Gauer, L., Baer, S., Valenti-Hirsch, M. P., De Saint-Martin, A., & Hirsch, E. (2024). Drug-resistant generalized epilepsies: Revisiting the frontiers of idiopathic generalized epilepsies. *Revue Neurologique*, *180*(4), 290-297. https://doi.org/10.1016/j.neurol.2024.03.001

Gazibara, T., Nikolovski, J., Lakic, A., Pekmezovic, T., & Kisic-Tepavcevic, D. (2014). Parental knowledge, attitudes, and behaviors towards children with epilepsy in Belgrade (Serbia). *Epilepsy & Behavior*, *41*, 210-216. https://doi.org/10.1016/j.yebeh.2014.09.062

Gee, J. P. (2014). *An introduction to discourse analysis: Theory and method*. Routledge. https://doi.org/10.4324/9781315819679

Gillespie, J.F., & Primavera, J. (2000). *Diverse families, competent families: innovations in research and preventive intervention practice.* Haworth Press, New York.

Glaser, B.G. and Strauss, A.L. (1967). The discovery of grounded theory. Chicago, Aldine.

Goldstein, M.D., & Harden, C.L. (2000). Epilepsy and anxiety. *Epilepsy & Behavior, 1,* 228-234. https://doi.org/10.1006/ebeh.2000.0080

Guerrini, R., Zaccara, G., la Marca, G., & Rosati, A. (2012). Safety and tolerability of antiepileptic drug treatment in children with epilepsy. *Drug safety, 35,* 519-533. https://doi.org/10.2165/11630700-000000000-00000

Gupta, G., & Shellhaas, R.A. (2020). Losing sleep: Considering caregivers of children with rare epilepsy syndromes. *The Journal of Pediatrics: X, 2.* https://doi.org/10.1016/j.ympdx.2020.100022

Guyatt, G.H., Feeny, D.H., & Patrick, D.L. (1993). Measuring health-related quality of life. *Annuals of internal medicine, 118,* 622-629. https://doi.org/10.7326/0003-4819-118-8-199304150-00009

Hankin, B.L. (2006). Adolescent depression: Description, causes, and interventions. *Epilpesy & Behavior, 8,* 102-114. https://doi.org/10.1016/j.yebeh.2005.10.012

Hansen, B., Szaflarski, M., Bebin, E.M., & Szaflarski, J.P. (2018). Affiliate stigma and caregiver burden in intractable epilepsy. *Epilepsy & Behavior, 85,* 1-6. https://doi.org/10.1016/j.yebeh.2018.05.028

Harden, J., Black, R., & Chin, R. F. (2016). Families' experiences of living with pediatric epilepsy: a qualitative systematic review. *Epilepsy & Behavior*, *60*, 225-237. https://doi.org/10.1016/j.yebeh.2016.04.034

Harrison, S., Cross, H., Harkness, F., & Vargha-Khadem, F. (2013). Pre-operative educational status of children with focal epilepsy. *Epilepsy & Behavior, 28,* 328. https://doi.org/10.1016/j.yebeh.2012.04.096

Hauser, W. A. (1994). The prevalence and incidence of convulsive disorders in children. *Epilepsia*, *35*, S1-S6. https://doi.org/10.1111/j.1528-1157.1994.tb05932.x

Hecimovic, H., Santos, J.M., Carter, J., Attarian, H.P., Fessler, A.J., Vahle, V., & Gilliam, F. (2012). *Epilepsy & Behavior, 24,* 426-429. https://doi.org/10.1016/j.yebeh.2012.05.005

Helde, G., Bovim, G., Brathen, G., & Brodtkorb, E. (2005). A structured, nurse-led intervention program improves quality of life in patients with epilepsy: A randomized, controlled trial. *Epilepsy & Behavior, 7,* 451-457. https://doi.org/10.1016/j.yebeh.2005.06.008

Henning, O., Alfstad, K. A., Nakken, K. O., & Lossius, M. I. (2019). A call for better information about epilepsy: The patients' perspective—An online survey. *Seizure*, *69*, 173-179. https://doi.org/10.1016/j.seizure.2019.04.015

Hermann, B,. & Whitman, S. (1991). Neurobiological, psychosocial, and pharmacological factors underlying interictal psychopathology in epilepsy. In: D. Smith, D. Treiman, M. Trimble (Eds.), *Advances in neurology, Vol. 55.* New York, NY: Raven Press.

Hesdorffer, D.C., Kroner, B.L., Shen, J., Farrell, K., Roberds, S., & Fureman, B. (2020). Factors associated with caregiver sleep quality related to children with rare epilepsy syndromes. *The Journal of Pediatrics: X, 2.* https://doi.org/10.1016/j.ympdx.2020.100021

Higgins, A., Downes, C., Varley, J., Doherty, C. P., Begley, C., & Elliott, N. (2019). Supporting and empowering people with epilepsy: contribution of the Epilepsy Specialist Nurses (SENsE study). *Seizure*, *71*, 42-49.

Higgins, A., Downes, C., Varley, J., Tyrell, E., Normand, C., Doherty, C. P., ... & Elliott, N. (2018). Patients with epilepsy care experiences: comparison between services with and without an epilepsy specialist nurse. *Epilepsy & Behavior*, *85*, 85-94. https://doi.org/10.1016/j.yebeh.2018.05.038

Hirsch, E., French, J., Scheffer, I. E., Bogacz, A., Alsaadi, T., Sperling, M. R., ... & Zhou, D. (2022). ILAE definition of the idiopathic generalized epilepsy syndromes: position statement by the ILAE task force on nosology and definitions. *Epilepsia*, *63*(6), 1475-1499. https://doi.org/10.1111/epi.17236

Hoare, P. (1984). Psychiatric disturbance in the families of epileptic children. *Developmental medicine & Child Neurology, 26,* 14-19. https://doi.org/10.1111/j.1469-8749.1991.tb05109.x

Hoare, P., & Kerley, S. (1991). Psychosocial adjustment of children with chronic epilepsy and their families. *Development Medicine & Child Neurology, 26,* 14-19. https://doi.org/10.1111/j.1469-8749.1991.tb05109.x

Hoie, B., Mykletun, A., Waaler, P.E., Skeidsvoll, H., & Sommerfelt, K. (2006). Executive functions and seizure-related factors in children with epilepsy in western Norway. *Developmental medicine & child neurology, 48,* 519-525. https://doi.org/10.1017/S0012162206001095

Hopkins, J. & Irvine, F. (2010). *Identifying and monitoring cost-effectiveness of the epilepsy specialist.* Retrieved from http://www.epilepsy.org.uk/research/fundedresearch/otherfunding/commissioneresearch

Hopkins, J., & Irvine, F. (2012). Qualitative insights into the role and practice of Epilepsy Specialist Nurses in England: a focus group study. Journal of advanced nursing, 68(11), 2443-2453. https://doi.org/10.1111/j.1365-2648.2012.05941.x

Hsieh, L., & Chiou, H. (2001). Comparison of epilepsy and asthma perception among preschool teachers in taiwan. *Epilepsia, 42,* 647-650. https://doi.org/10.1046/j.1528-1157.2001.39200.x

Ijff, D.M., & Aldenkamp, A.P. (2013). Cognitive side-effects of antiepileptic drugs in children. *Handbook of Clinical Neurology, 111,* 707-718. https://doi.org/10.1016/B978-0-444-52891-9.00073-7

Im, Y., Cho, Y., & Kim, D. (2019). Family management style as a mediator between parenting stress and quality of life of children with epilepsy. *Journal of pediatric nursing, 45,* e73-e78. https://doi.org/10.1016/j.pedn.2018.12.007

Jambaque, I., Dellatolas, G., Dulac, O., Ponsot, G., & Signoret, J. (1993). Verbal and visual memory impairment in children with epilepsy. *Neuropsychologia, 31,* 1321-1337. https://doi.org/10.1016/0028-3932(93)90101-5

James, A. C., Reardon, T., Soler, A., James, G., & Creswell, C. (2020). Cognitive behavioural therapy for anxiety disorders in children and adolescents. *Cochrane database of systematic reviews*, (11). https://doi.org/10.1002/14651858.CD013162.pub2

Jantzen, S., Müller-Godeffroy, E., Hallfahrt-Krisl, T., Aksu, F., Püst, B., Kohl, B., … Thyen, U. (2009). FLIP&FLAP- A training programme for children and adolescents with epilepsy, and their parents. *Seizure, 17(7),* 478-486. https://doi.org/10.1016/j.seizure.2009.04.007

Jarvie, S., Espie, C. A., & Brodie, M. J. (1993). The development of a questionnaire to assess knowledge of epilepsy: 1—general knowledge of epilepsy. *Seizure-European Journal of Epilepsy*, *2*(3), 179-185. https://doi.org/10.1016/S1059-1311(05)80125-6

Jensen, F.E. (2011). Epilepsy as a spectrum disorder: Implications from novel clinical and basic neuroscience. *Epilepsia, 52(1),* 1-6. https://doi.org/10.1111/j.1528-1167.2010.02904.x

Jocic-Jakubi, B., & Jovic, N.J. (2006). Verbal memory impairment in children with focal epilepsy. *Epilepsy & Behavior, 9,* 432-439. https://doi.org/10.1016/j.yebeh.2006.07.010

Joint Epilepsy Council. (2011). *Epilepsy prevalence, incidence and other statistics*. JEC, Leeds.

Johnson, E.C., Atkinson, P., Muggeridge, A., Cross, H.J., & Reilly, C. (2021). Epilepsy in schools: Views on educational and therapeutic provision, understanding of epilepsy and seizure management. *Epilepsy & Behaviour, 122,* 108179. https://doi.org/10.1177/0883073808314162

Johnson, K., McGowan, T., & Dunkley, C. (2010). A review of epilepsy specialist nurse's clinical activity and impact on paediatric admissions. *British Paediatric Neurology Association*.

Jones, C., Atkinson, P., Cross, J.H., & Reilly, C. (2018). Knowledge of and attitudes towards epilepsy among teachers: A systematic review. *Epilepsy & Behavior, 87,* 59-68. https://doi.org/10.1016/j.yebeh.2018.06.044

Jones, C., Atkinson, P., Memon, A., Dabydeen, L., Das, K. B., Cross, J. H., ... & Reilly, C. (2019). Experiences and needs of parents of young children with active epilepsy: a population-based study. *Epilepsy & Behavior*, *90*, 37-44. https://doi.org/10.1016/j.yebeh.2018.10.031

Jones, C., & Reilly, C. (2016). Parental anxiety in childhood epilepsy: A systematic review. *Epilepsia, 57,* 529-537. https://doi.org/10.1111/epi.13326

Jones, F.J.S., Ezzeddine, F.L., Herman, S.T., Buchhalter, J., Fureman, B., & Moura, L. (2020). The feasibility assessment of functioning and quality of life patient reported outcome measures in adult epilepsy clinics: A systematic review. *Epilepsy & Behavior, 102,* 106704. https://doi.org/10.1016/j.yebeh.2019.106704

Jones, J.E., Hermann, B.P., Barry, J.J., Gilliam, F.G., Kanner, A.M., & Meador, K.J. (2003). Rates and risk factors for suicide, suicidal ideation, and suicide attempts in chronic epilepsy. *Epilepsy & Behavior, 4,* S31-S38. https://doi.org/10.1016/j.yebeh.2003.08.019

Joplin, S., Gascoigne, M., Barton, B., Webster, R., Gill, D., Lawson, J. A., ... & Lah, S. (2022). Accelerated long-term forgetting in children with temporal lobe epilepsy: a timescale investigation of material specificity and executive skills. *Epilepsy & Behavior*, *129*, 108623. https://doi.org/10.1016/j.yebeh.2020.107471

Kampra, M., Tzerakis, N.G., Losidis, S., Katsarou, E., Voudris, K., Mastroyianni, S., … & Gatzonis, S. (2016). Teachers' knowledge about epilepsy in Greece: Information sources and attitudes towards children with epilepsy during school time. *Epilepsy & Behavior, 60,* 218-224. https://doi.org/10.1016/j.yebeh.2016.04.004

Kankirawatana, P. (1999). Epilepsy awareness among school teachers in Thailand. *Epilepsia, 40,* 497-501. https://doi.org/10.1111/j.1528-1157.1999.tb00747.x

Ketter, T.A., Post, R.M., & Theodore, W.H. (1999). Positive and negative psychiatric effects of antiepileptic drugs in patients with seizure disorders. *Neurology, 53,* S53-S67.

Killip, S., Mabfoud, Z., & Pearce, K. (2004). What is an intracluster correlation coeffient? Crucial concepts for primary care researchers. *Annals of Family Medicine, 2,* 204-208. https://doi.org/10.1370/afm.141

Kim-Cohen, J., Caspi, A., Moffitt, T.E., Harrington, H., Milne, B.J., & Poulton, R. (2003). Prior juvenile diagnoses in adults with mental disorder: developmental follow-back of a prospective-longitudinal cohort. *Archives of general psychiatry, 60,* 709-717. https://doi.org/10.1001/archpsyc.60.7.709

Kirkpatrick, M., Dunkley, C., Ferrie, C., Flower, D., Waldron, B., Whitehouse, W. P., ... & Appleton, R. (2014). Guidelines, training, audit, and quality standards in children's epilepsy services: closing the loop. *Seizure*, *23*(10), 864-868. http://dx.doi.org/10.1016/j.seizure.2014.07.009

Kostis, J. B., & Dobrzynski, J. M. (2020). Limitations of randomized clinical trials. *The American journal of cardiology*, *129*, 109-115. https://doi.org/10.1016/j.amjcard.2020.05.011

Kroner, B.L., Ardini, M., Bumbut, A., & Gaillard, W.D. (2018). Parental perspectives of the impact of epilepsy and seizures on siblings of children with epilepsy. *Journal of Pediatric Health Care, 32,* 348-355. https://doi.org/10.1016/j.pedhc.2017.12.004

Law, N., Widjaja, E., & Smith, M.L. (2017). Unique and shared areas of cognitive function in children with intractable frontal or temporal lobe epilepsy. *Epilepsy & Behavior, 80,* 157-162. https://doi.org/10.1016/j.yebeh.2017.12.035

Lagae, L. (2006). Cognitive side effects of anti-epileptic drugs: the relevance in childhood epilepsy. *Seizure, 15,* 235-241. https://doi.org/10.1016/j.seizure.2006.02.013

Larson, A.M., Ryther, R.C., Jennesson, M., Geffrey, A.L., Bruno, P.L., Anagnos, C.J., Shoeb, A.H., Thibert, R.L., & Thiele, E.A. (2012). Impact of pediatric epilepsy and behaviors in children and parents. *Epilepsia, 53*(7), 1162-1169. https://doi.org/10.1111/j.1528-1167.2012.03515.x

Leone, M.A., Beghi, E., Righini, C., Apolone, G., & Mosconi, P. (2005). Epilepsy and quality of life in adults: A review of instruments. *Epilepsy research, 66,* 23-44. https://doi.org/10.1016/j.eplepsyres.2005.02.009

Lewinsohn, P.M., Clarke, G.N., Seeley, J.R., & Rohde, P. (1994). Major depression in community adolescents: age at onset, episode duration, and time to recurrence. *Journal of the American Academy of Child & Adolescent Psychiatry, 33,* 809-818. https://doi.org/10.1097/00004583-199407000-00006

Lewis, S. A., Noyes, J., & Mackereth, S. (2010). Knowledge and information needs of young people with epilepsy and their parents: Mixed-method systematic review. *BMC pediatrics*, *10*, 1-17. https://doi.org/10.1186/1471-2431-10-103

Link, B.G., & Phelan, J.C. (2006). Stigma and its public health implications. *Lancet, 367,* 528-529. https://doi.org/10.1016/S0140-6736(06)68184-1

Lippe, S., Bulteau, C., Dorfmuller, G., Audren, F., Delalande, O., & Jambaque, I. (2010). Cognitive outcome of parietooccipital resection in children with epilepsy. *Epilepsia, 51,* 2047-2057. https://doi.org/10.1111/j.1528-1167.2010.02651.x

Locatelli, G., Ausili, D., Stubbings, V., Di Mauro, S. & Luciani, M. (2021). The epilepsy specialist nurse: A mixed-methods case study on the role and activities. *Seizure: European Journal of Epilepsy, 85,* 57-63. https://doi.org/10.1016/j.seizure.2020.12.013

Long, L., Reeves, A. L., Moore, J. L., Roach, J., & Pickering, C. T. (2000). An assessment of epilepsy patients' knowledge of their disorder. *Epilepsia*, *41*(6), 727-731. https://doi.org/10.1111/j.1528-1157.2000.tb00235.x

Loring, D.W., Marino, S. & Meador, K.J. (2007). Neuropsychological and behavioral effects of anti-epilepsy drugs. *Neuropsychology review, 17,* 413-425. https://doi.org/10.1007/s11065-007-9043-9

Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour research and therapy*, *33*(3), 335-343. https://doi.org/10.1016/0005-7967(94)00075-U

Lv, R., Wu, L., Jin, L., Lu, Q., Wang, M., Qu, Y., & Liu, H. (2009). Depression, anxiety and quality of life in parents of children with epilepsy. *Acta Neurologica Scandinavica, 120,* 335-341. https://doi.org/10.1111/j.1600-0404.2009.01184.x

Maccoby, E.E., & Martin, J.A. (1983). Socialization in the context of the family: Parent-child interaction. In P.H. Mussen & E.M. Hetherington (Eds.), *Handbook of child psychology: Socialization, Personality and Social Development* (pp. 1-101) New York: Wiley.

MacDonald, D., Torrance, N., Wood, S., & Womersley, J. (2000). General-practice-based nurse specialists—taking a lead in improving the care of people with epilepsy. *Seizure*, *9*(1), 31-35. https://doi.org/10.1053/seiz.1999.0356

MacEachern, S.J., D'Alfonso, S., McDonald, R.J., Thornton, N., Forkert, N.D., & Buchhalter, J.R. (2017). Most children with epilepsy experience postictal phenomena, often preventing a return to normal activities of childhood. *Pediatric Neurology, 72,* 42-50. https://doi.org/10.1016/j.pediatrneurol.2017.03.002

MacLeod, J.S., & Austin, J.K. (2003). Stigma in the lives of adolescents with epilepsy: a review of the literature. *Epilepsy & Behavior, 4,* 112-117. https://doi.org/10.1016/S1525-5050(03)00007-6

Mahendran, M., Speechley, K. N., & Widjaja, E. (2017). Systematic review of unmet healthcare needs in patients with epilepsy. *Epilepsy & Behavior*, *75*, 102-109. https://doi.org/10.1016/j.yebeh.2017.02.034

Malhi, P., & Singhi, P. (2005). Correlates of quality of life with epilepsy. *Indian journal of paediatrics, 72,* 131- 135. https://doi.org/10.1007/BF02760697

Martland, T., & Cross, J.H. (2009). Best clinical and research practice in pediatric neurology. *Epilepsy & Behavior, 15,* S51-S54. https://doi.org/10.1016/j.yebeh.2009.03.018

Masri, A., Aburahma, S., Khasawneh, A., Qudah, A. A., Nafi, O., Al Momani, M., & Khatib, F. (2017). Parental knowledge and attitudes towards epilepsy–A study from Jordan. *Seizure*, *53*, 75-8. https://doi.org/10.1016/j.seizure.2017.11.006

Maxwell, J. A. (2012). *A realist approach for qualitative research*. Sage.

McCusker, C., Kennedy, P., Anderson, J., Hicks, E., Hanrahan, D. (2002). Adjustment in children with intractable epilepsy: importance of seizure duration and family factors. *Developmental Medicine & Child Neurology, 44,* 681-687. https://doi.org/10.1017/S0012162201002754

McDermott, S., Mani, S., Krishnaswami, S.A. (1995). A population-based analysis of specific behaviour problems associated with childhood seizures. *Journal of Epilepsy, 8,* 110-118. https://doi.org/10.1016/0896-6974(95)00019-A

McEwan, M. J., Espie, C. A., & Metcalfe, J. (2004). A systematic review of the contribution of qualitative research to the study of quality of life in children and adolescents with epilepsy. *Seizure*, *13*(1), 3-14. https://doi.org/10.1016/S1059-1311(03)00081-5

McEwan, L,. et al. (2007). Knowledge of and attitudes expressed toward epilepsy by carers of people with epilepsy: A UK perspective. *Epilepsy & Behavior, 11*, 13-19. https://doi.org/10.1016/j.yebeh.2007.02.019

McLaughlin, R. M., Schraegle, W. A., Nussbaum, N. L., & Titus, J. B. (2018). Parental coping and its role in predicting health-related quality of life in pediatric epilepsy. *Epilepsy & Behavior*, *87*, 1-6. https://doi.org/10.1016/j.yebeh.2018.08.009

McNelis, A. M., Buelow, J., Myers, J., & Johnson, E. A. (2007). Concerns and needs of children with epilepsy and their parents. *Clinical Nurse Specialist*, *21*(4), 195-202. https://doi.org/10.1097/01.NUR.0000280488.33884.1d

McNelis, A.M., Dunn, D.W., Johnson, C.S., Austin, J.K., & Perkins, S.M. (2007). Academic performance in children with new-onset seizures and asthma: a prospective study. *Epilepsy Behavior, 10,* 311-318. https://doi.org/10.1016/j.yebeh.2006.12.012

Meads, C., Burls, A. & Bradley, P. (2002). Systematic reviews of specialist epilepsy services. *Seizure, 11*, 90-98. https://doi.org/10.1053/seiz.2002.0595

Menlove, L., & Reilly, C. (2015). Memory in children with epilepsy: A systematic review. *Seizure, 25,* 126-135. https://doi.org/10.1016/j.seizure.2014.10.002

Mensah, M.K., & Kuranchie, A. (2013). Influence of parenting styles on the social development of children. *Academic Journal of Interdisciplinary Studies, 2,* 123-129. https://doi.org/10.5901/ajis.2013.v2n3p123

Mercier, A., Dorris, L., Brunklaus, A., Symonds, J. D., Zuberi, S. M., Finch, T., ... & Eldred, C. (2025). Trauma, coping, and adjustment when parenting a child with Dravet syndrome. *European Journal of Paediatric Neurology*, *54*, 96-106. https://doi.org/10.1016/j.ejpn.2025.01.002

Michaelis, R., Tang, V., Goldstein, L. H., Reuber, M., LaFrance Jr, W. C., Lundgren, T., ... & Wagner, J. L. (2018). Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International League Against Epilepsy Psychology Task Force. *Epilepsia*, *59*(7), 1282-1302. https://doi.org/10.1111/epi.14444

Mielke, J., Adamolekum, B., Ball, D., & Mundanda, T. (1997). Knowledge and attitudes of teachers towards epilepsy in Zimbabwe. *Acta Neurologica Scandinavica, 96,* 133-137. https://doi.org/10.1111/j.1600-0404.1997.tb00254.x

Miles, M.B., & Hubermann, A.M. (1994). *Qualitative data analysis. 2nd Ed.* Thousand Oaks, CA: Sage Publications.

Miller, V., Palermo, T.M., & Grewe, S.D. (2003). Quality of life in pediatric epilepsy: demographic and disease-related predictors and comparison with healthy controls. *Epilepsy & Behavior, 4,* 36-42. https://doi.org/10.1016/S1525-5050(02)00601-7

Mills, N., Bachmann, M. O., Harvey, I., Hine, I. & McGowan, M. (1999). Effect of a primary-care-based epilepsy specialist nurse service on quality of care from the patients' perspective: quasi-experimental evaluation. *Seizure, 8,* 1-7. https://doi.org/10.1053/seiz.1998.0232

Mills, N., Campbell, R., & Bachmann, M. O. (2002). What do patients want and get from a primary care epilepsy specialist nurse service?. *Seizure*, *11*(3), 176-183. https://doi.org/10.1053/seiz.2001.0615

Mims, J. (1997). Self-esteem, behaviour, and concerns surrounding epilepsy in siblings of children with epilepsy. *Journal of Child Neurology, 12,* 187-192. https://doi.org/10.1177/088307389701200307

Moavero, R., Santarone, M.E., Galasso, C., & Curatolo, P. (2017). Cognitive and behavioural effects of new antiepileptic drugs in pediatric epilepsy. *Brain and development, 39,* 464-469. https://doi.org/10.1016/j.braindev.2017.01.006

Moffat, C., Dorris, L., Connor, L., & Espie, C. A. (2009). The impact of childhood epilepsy on quality of life: A qualitative investigation using focus group methods to obtain children's perspectives on living with epilepsy. *Epilepsy & Behavior*, *14*(1), 179-189. https://doi.org/10.1016/j.yebeh.2008.09.025

Molin, K. R., Egerod, I., Valentiner, L. S., Lange, P., & Langberg, H. (2016). General practitioners' perceptions of COPD treatment: thematic analysis of qualitative interviews. *International journal of chronic obstructive pulmonary disease*, 1929-1937. https://doi.org/10.2147/COPD.S108611

Moreira, H., Carona, C., Silva, N., Frontini, R., Bullinger, M., & Canavarro, M.C. (2013). Psychological and quality of life outcomes in pediatric populations: A parent-child perspective. *The journal of paediatrics, 163,* 1471-1478. https://doi.org/10.1016/j.jpeds.2013.06.028

Mott, J., Shellhaas, R.A., & Joshi, S.M. (2012). Knowledge of epilepsy and preferred sources of information among elementary school teachers. *Journal of Child Neurology, 28,* 740-744. https://doi.org/10.1177/0883073812451775

Mula, M., & Monaco, F. (2009). Antiepileptic drugs and psychopathology of epilepsy: an update. *Epileptic disorders, 11,* 1-9. https://doi.org/10.1684/epd.2009.0238

Mula, M., & Sander, J.W. (2012). Negative effects of antiepileptic drugs on mood in patients with epilepsy. *Drug Safety, 30,* 555-567. https://doi.org/10.2165/00002018-200730070-00001

Mullen, S. A., Berkovic, S. F., ILAE Genetics Commission, Berkovic, S. F., Lowenstein, D. H., Kato, M., ... & Jiang, Y. (2018). Genetic generalized epilepsies. *Epilepsia*, *59*(6), 1148-1153. https://doi.org/10.1111/epi.14042

Nabbout, R., Camfield, C.S., Andrade, D.M., Arzimanoglou, A., Chiron, C., Cramer, J.A., … & Camfield, P.R. (2017). Treatment issues for children with epilepsy transitioning to adult care. *Epilepsy & Behavior, 69,* 153-160. https://doi.org/10.1016/j.yebeh.2016.11.008

Nadkarni, J., Jain, A., & Dwivedi, R. (2011). Qulaity of life in children with epilepsy. *Annuals of Indian Academy of Neurology, 14,* 279-282. https://doi.org/10.4103/0972-2327.91948

Nagan, M., Caffarelli, M., Donatelli, S., & Rosman, N. P. (2017). Epilepsy or a seizure disorder? Parental knowledge and misconceptions about terminology. *The Journal of Pediatrics*, *191*, 197-203. https://doi.org/10.1016/j.jpeds.2017.08.068

National Institute for Health and Care Excellence. (2012). *Clinical guideline [CG137]*. NICE, London.

National Institute for Health and Care Excellence. (2022). *Nice guideline: methods [NG217]. Epilepsies in children, young people and adults: diagnosis and management.* NICE, London.

Nevin, S. M., Wakefield, C. E., Schilstra, C. E., McGill, B. C., Bye, A., & Palmer, E. E. (2020). The information needs of parents of children with early-onset epilepsy: a systematic review. *Epilepsy & Behavior*, *112*, 107382. https://doi.org/10.1016/j.yebeh.2020.107382

Newman, B.M., & Newman, P.R. (2015). *Development through life: A psychosocial approach, 12th Ed.* Stamford, CT: Cengage Learning

Nguyen, S., Pertini, M., & Kettler, L. (2015). Parental cognitive appraisals and coping behaviours following child's epilepsy diagnosis: A qualitative study. *Clinical child psychology and psychiatry*, *20*(1), 20-38. https://doi.org/10.1177/1359104513494089

Nolan, K., Camfield, C.S., & Camfield, P.R. (2008). Coping with a child with Dravet syndrome: insights from families. *Journal of Child Neurology, 23,* 690-694. https://doi.org/10.1177/0883073808314162

Okumura, A., Saitoh, S., Natsume, J., Yamamoto, H., Kurahashi, H., Numoto, S. (2020). Attitudes of school teachers toward epilepsy in Nagoya, Japan. *Epilepsy & Behavior, 103,* 106359. https://doi.org/10.1016/j.yebeh.2019.06.005

Oguz, A., Kurul, S., Dirik, E., & Eylul, D. (2002). Relationship of epilepsy-related factors to anxiety and depression scores in epileptic children. Journal of child neurology, 17, 37-40. https://doi.org/10.1177/088307380201700109

Oostrom, K.J., Schouten, A., Kruitwagen, C.L.J.J., Peters, A.C.B., & Jennekens-Schinkel, A. (2003). Behavioral problems in children with newly diagnosed idiopathic or cyptogenic epilepsy attending normal schools are in majority not persistent. *Epilepsia, 44,* 97-106. https://doi.org/10.1046/j.1528-1157.2003.18202.x

Oostrom, K.J., Schouten, A., Olthof, T., Peters, A.C.B., & Jennekens-Schinkel., A. (2000). Negative emotions in children with newly diagnosed epilepsy. *Epilepsia, 41,* 326-331. https://doi.org/10.1111/j.1528-1157.2000.tb00163.x

Operto, F.F., Mazza, R., Pastorino, G.M.G., Campanozzi, S., Verrotti, A., Coppola, G. (2019). Parental stress in a sample of children with epilepsy. *Neurologica, 140,* 87-92. https://doi.org/10.1111/ane.13106

Otero, S. (2009). Psychopathology and psychological adjustment in children and adolescents with epilepsy. *World Journal of Pediatrics, 5,* 12-17. https://doi.org/10.1007/s12519-009-0002-9

O'Toole, S., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2016). Talking about epilepsy: challenges parents face when communicating with their child about epilepsy and epilepsy-related issues. *Epilepsy & Behavior*, *57*, 9-15. https://doi.org/10.1016/j.yebeh.2016.01.013

Ott, D., Siddarth, P., Gurbani, A., Koh, S., Tournay, A., Donald-Shiels, W., & Caplan, R. (2003). Behavioral disorders in pediatric epilepsy. *Epilepsia, 44,* 591-597. https://doi.org/10.1046/j.1528-1157.2003.25002.x

Parrish, J., Geary, E., Jones, J., Seth, R., Hermann, B., & Seidenberg, M. (2007). Executive functioning in childhood epilepsy: parent-report and cognitive assessment. *Developmental medicine & child neurology, 49,* 412-416. https://doi.org/10.1111/j.1469-8749.2007.00412.x

Pianta, R.C., & Lothman, D.J. (1994). Predicting behavior problems in children with epilepsy: child factors, disease factors, family stress, and child-parent interaction. *Child development, 65,* 1415-1428. https://doi.org/10.1111/j.1467-8624.1994.tb00826.x

Pennington, B.F., & Ozonoff, S. (1996). Executive functions and developmental psychopathology. *Journal of child psychology and psychiatry, 37,* 51-87. https://doi.org/10.1111/j.1469-7610.1996.tb01380.x

Pfäfflin, M., Schmitz, B., & May, T. W. (2016). Efficacy of the epilepsy nurse: results of a randomized controlled study. *Epilepsia*, *57*(7), 1190-1198. https://doi.org/10.1111/epi.13424

Pompili, M., Girardi, P., Ruberto, A., & Tatarelli, R. (2005). Suicide in the epilepsies: A meta-analytic investigation of 29 cohorts. *Epilepsy & Behavior, 7,* 305-310. https://doi.org/10.1016/j.yebeh.2005.05.010

Prasad, A.N., & Corbett, B. (2016). Epilepsy and its impact on psychosocial outcomes in Canadian children: Data from the National Longitudinal Study of Children and Youth (NLSCY). *Epilepsy Research, 128,* 119-125. https://doi.org/10.1016/j.eplepsyres.2016.10.019

Prevos-Morgant, M., Leavy, Y., Chartrand, D., Jurasek, L., Shafer, P. O., Shinnar, R., & Goodwin, M. (2019). Benefits of the epilepsy specialist nurses (ESN) role, standardized practices and education around the world. *Revue neurologique*, *175*(3), 189-193. https://doi.org/10.1016/j.neurol.2018.10.003

Puka, K., Ferro, M.A., Anderson, K.K., & Speechley, K.N. (2018). Health-related quality of life in mothers of children with epilepsy: 10 years after diagnosis. *Quality of Life Research, 27,* 969-977. https://doi.org/10.1007/s11136-017-1778-z

Puka, K., Tavares, T.P., Anderson, K.K., Ferro, M.A., & Speechley, K.N. (2018). A systematic review of quality of life in parents of children with epilepsy. *Epilepsy & Behavior, 82,* 38-45. https://doi.org/10.1016/j.yebeh.2018.03.008

Rani, A., & Thomas, P.T. (2019). Stress and perceived stigma among parents of children with epilepsy. *Neurological Sciences, 40,* 1363-1370. https://doi.org/10.1007/s10072-019-03822-6

Rawlings, G. H., Brown, I., Stone, B., & Reuber, M. (2017). Written accounts of living with epilepsy: A thematic analysis. *Epilepsy & Behavior*, *72*, 63-70. https://doi.org/10.1016/j.yebeh.2017.04.026

Reilly, C., Agnew, R., & Neville, B.G.R. (2011). Depression and anxiety in childhood epilepsy: A review. *Seizure, 20,* 589-597. https://doi.org/10.1016/j.seizure.2011.06.004

Reilly, C., Atkinson, P., Das., Chin, R.F.M.C., Aylett, S.E., Burch, V., … Neville, B.G.R. (2014). Neurobehavioral comorbidities in children with active epilepsy: A population-based study. *Pediatrics, 6,* e1586-e1596. https://doi.org/10.1542/peds.2013-3787

Reilly, C., Atkinson, P., Memon, A., Jones, C., Dabydeen, L., Cross, J.H., … Scott, R.C. (2019). Autism, ADHD, and parent-reported behavioural difficulties in young children with epilepsy. *Seizure, 71,* 233-239. https://doi.org/10.1016/j.yebeh.2018.10.016

Reilly, C., Atkinson, P., Memon, A., Jones, C., Dabydeen, L., Das, K.B., … Scott, R.C. (2018). Parenting stress and perceived stigma in mothers of young children with epilepsy: A case-control study. *Epilepsy & Behavior, 89,* 112-117. https://doi.org/10.1016/j.yebeh.2018.10.016

Reilly, C., Taft, C., Nelander, M., Malmgren, K., & Olsson, I. (2015). Health-related quality of life and emotional well-being in parents of children with epilepsy referred for presurgical evaluation in Sweden. *Epilepsy & Behavior, 53,* 10-14. https://doi.org/10.1016/j.yebeh.2015.09.025

Ridsdale, L., Kwan, I., & Cryer, C. (1999). The effect of a special nurse on patients knowledge of epilepsy and their emotional state. *British Journal of General Practice, 49,* 285-289. https://doi.org/10.1136/bmj.314.7074.120

Ridsdale, L., Kwan, I., Cryer, C., & the Epilepsy Care Evaluation Group (2000). Newly diagnosed epilepsy: Can nurse specialists help? *Epilepsia, 41,* 1014-1019. https://doi.org/10.1136/bmj.314.7074.120

Ridsdale, L., Kwan, I., & Morgan, M. (2003). How can a nurse intervention help people with newly diagnosed epilepsy?: A qualitative study of patients' views. *Seizure*, *12*(2), 69-73. https://doi.org/10.1016/S1059–1311(02)00178-4

Ridsdale, L., Robins, D., Cryer, C., Williams, H. & the Epilepsy Care Evaluation Group (1997). Feasibility and effects of nurse run clinics for patients with epilepsy in general practice: randomised controlled trial. BMJ, 314, 120-122. https://doi.org/10.1136/bmj.314.7074.120

Roberts, J., & Whiting, C. (2011). Caregivers of school children with epilepsy: findings of a phenomenological study. *British Journal of Special Education, 38,* 169-177. https://doi.org/10.1111/j.1467-8578.2011.00519.x

Rodenburg, R., Meijer, A., Dekovic, M., & Aldenkamp, A. (2005). Family factors and psychopathology in children with epilepsy: a literature review. *Epilepsy Behaviour, 6,* 488-503. https://doi.org/10.1016/j.yebeh.2005.03.006

Rodenburg, R., Meijer, A., Dekovic, M., & Aldenkamp, A. (2006). Family predictors of psychopathology in children with epilepsy. *Epilepsia, 47,* 601-614. https://doi.org/10.1111/j.1528-1167.2006.00475.x

Rodenburg, R., Meijer, A., Dekovic, M., & Aldenkamp, A. (2007). Parents of children with enduring epilepsy: Predictors of parenting stress and parenting. *Epilepsy & Behavior,11,* 197-207. https://doi.org/10.1016/j.yebeh.2007.05.001

Rodenburg, R., Meijer, A., Scherphof, C., Carpay, J.A., Augustijn, P., Aldenkamp, A., Dekovic, M. (2013). Parenting and restrictions in childhood epilepsy. *Epilepsy & Behavior, 27,* 497-503. https://doi.org/10.1016/j.yebeh.2013.01.026

Rodenburg, R., Stams, G., Meijer, A., Aldenkamp, A., & Dekovic, M. (2005). Psychopathology in children with epilepsy: a meta-analysis. *Journal of Paediatric Psychology, 30,* 453-468. https://doi.org/10.1093/jpepsy/jsi071

Rodenburg, R., Wagner, J.L., Austin, J., Kerr, M., & Dunn, D.W. (2011). Psychosocial issues for children with epilepsy. *Epilepsy & Behavior, 22,* 47-54. https://doi.org/10.1016/j.yebeh.2011.04.063

Ronen, G.M., Rosenbaum, P., Law, M., & Streiner, D.L. (1999). Health-related quality of life in childhood epilepsy: the results of children's participation in identifying the components. *Developmental medicine & child neurology, 41,* 554-559. https://doi.org/10.1017/S0012162299001176

Ronen, G.M., Streiner, D.L., & Rosenbaum, P. (2003a). Health-related quality of life in childhood epilepsy: Moving beyond seizure control with minimal adverse effects. *Health and Quality of Life Outcomes, 1,* 36-46. https://doi.org/10.1186/1477-7525-1-36

Ronen, G.M., Streiner, D.L., & Rosenbaum, P. (2003b). Health-related quality of life in children with epilepsy: development and validation of self-report and parent proxy measures. *Epilepsia, 44,* 598-612. https://doi.org/10.1046/j.1528-1157.2003.46302.x

Rosenkranz, M. A., Dunne, J. D., & Davidson, R. J. (2019). The next generation of mindfulness-based intervention research: what have we learned and where are we headed?. *Current opinion in psychology*, *28*, 179-183. https://doi.org/10.1016/j.copsyc.2018.12.022

Royal College of Nursing, (2013). *Specialist nursing of children and young people with Epilepsy.* Retrieved from https://www.epilepsy.org.uk/sites/epilepsy/files/professionals/Nurse%20portfolio%20docs/ENS%20competencies.pdf

Royal College of Paediatrics and Child Health (2012). *Epilepsy12 Results.* Retrieved from: www.rcpch.ac.uk/child-health

Royal College of Paediatrics and Child Health (2022). *Epilepsy12 Combined organisational and clinical audits.* Retrieved from: https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022

Rutter, M., Graham, P., and Yule, W. (1970). *A neuropsychiatric study in childhood.* London: William Heinemann Medical.

Ryvlin, R., Cross, J.H., & Rheims, S. (2014). Epilepsy surgery in children and adults. *The Lancet Neurology, 13,* 1114-1126. https://doi.org/10.1016/S1474-4422(14)70156-5

Rzezak, P., Valente, K.D., & Duchowny, M.S. (2014). Temporal lobe epilepsy in children: Executive and mnestic impairments. *Epilepsy & Behavior, 31,* 117-122. https://doi.org/10.1016/j.yebeh.2013.12.005

Sacks, H., Schegloff, E.A., & Jefferson, G. (1974). A simplest systematics for the organization of turn-taking for conversation. *Language. 50*(4), 696–735. https://dx.doi.org/10.1353/lan.1974.0010.

Sales, E. (2003). Family burden and quality of life. *Quality of life research, 12*(1), 33-41. https://doi.org/10.1023/A:1023513218433

Scambler, A., Scambler, G., Ridsdale, L., & Robins, D. (1996). Towards an evaluation of the effectiveness of an epilepsy nurse in primary care. *Seizure, 5,* 255-258. https://doi.org/10.1016/S1059-1311(96)80017-3

Scheffer, I. E., Berkovic, S., Capovilla, G., Connolly, M. B., French, J., Guilhoto, L., ... & Zuberi, S. M. (2017). ILAE classification of the epilepsies: Position paper of the ILAE Commission for Classification and Terminology. *Epilepsia*, *58*(4), 512-521. https://doi.org/10.1111/epi.13709

Scheffer, I. E., French, J., Valente, K. D., Auvin, S., Cross, J. H., & Specchio, N. (2025). Operational definition of developmental and epileptic encephalopathies to underpin the design of therapeutic trials. *Epilepsia*, *66*(4), 1014-1023. https://doi.org/10.1111/epi.18265

Schoenfeld, J., Seidenberg, M., Woodard, A., Hecox, K., Inglese, C., Mack, K., Hermann, B. (1999). Neuropsychological and behavioral status of children with complex partial seizures. *Developmental Medicine & Child Neurology, 41,* 724-731. https://doi.org/10.1017/S0012162299001486

Schraegle, W.A., & Titus, J.B. (2016). Executive function and health-related quality of life in pediatric epilepsy. *Epilepsy & Behavior, 62,* 20-26. https://doi.org/10.1016/j.yebeh.2016.06.006

Schwarz, T., Schmidt, A. E., Bobek, J., & Ladurner, J. (2022). Barriers to accessing health care for people with chronic conditions: a qualitative interview study. *BMC Health Services Research*, *22*(1), 1037. https://doi.org/10.1186/s12913-022-08426-z

Sherman, E.M.S., Slick, D.J., & Eyrl, K.L. (2006). Executive dysfunction is a significant predictor of poor quality of life in children with epilepsy. *Epilepsia, 47,* 1936-1942. https://doi.org/10.1111/j.1528-1167.2006.00816.x

Sheth, R. D. (2002). Adolescent issues in epilepsy. *Journal of child neurology*, *17*(2_suppl), 2S23-2S27. https://doi.org/10.1177/08830738020170020801

Shore, C.P., Austin, J.K., & Dunn, D.A. (2004). Maternal adaptation to a child's epilepsy. *Epilepsy & Behavior, 5,* 557-568. https://doi.org/10.1016/j.yebeh.2004.04.015

Shore, C., Austin, J., Huster, G., & Dunn, D. (2002). Identifying risk factors for maternal depression in families of adolescents with epilepsy. *Journal for specialists in pediatric nursing, 7,* 71-80. https://doi.org/10.1111/j.1744-6155.2002.tb00153.x

Shore, C., Perkins, S., & Austin, J. (2008). The seizures and epilepsy education (SEE) program for families of children with epilepsy: A preliminary study. *Epilepsy & Behavior, 12,* 157-164. https://doi.org/10.1016/j.yebeh.2007.10.001

Sillianpää, M. (2004). Learning disability: occurrence and long-term consequences in childhood-onset epilepsy. *Epilepsy & Behavior, 5,* 937-944. https://doi.org/10.1016/j.yebeh.2004.08.008

Sillianpää, M. & Cross, J.H. (2009). The psychosocial impact of epilepsy in childhood. *Epilepsy & Behavior, 15,* S5-S10. https://doi.org/10.1016/j.yebeh.2009.03.007

Sillianpää, M., Haataja, L., & Shinnar, S. (2004). Perceived impact of childhood-onset epilepsy on quality of life as an adult. *Epilepsia, 45,* 971-977. https://doi.org/10.1111/j.0013-9580.2004.44203.x

Smith, G., Wagner, J., Andrews, J., Austin, J., Mueller, M., Carter, E., & Griesemer, K. (2014). Caregiving in pediatric epilepsy: results of focus groups and implications for research and practice. *Epilepsy & Behavior, 34,* 34-41. https://doi.org/10.1016/j.yebeh.2014.03.002

Smith, G., Modi, A. C., Johnson, E. K., Shegog, R., Austin, J. K., & Wagner, J. L. (2018). Measurement in pediatric epilepsy self-management: A critical review. *Epilepsia*, *59*(3), 509-522. https://doi.org/10.1111/epi.13992

Speechley, K.N., Ferro, M.A., Camfield, C.S., Huang, W., Levin, S.D., Smith, M.L., … Zou, G. (2012). Quality of life in children with new-onset epilepsy. *Neurology, 79,* 1548-1555. https://doi.org/10.1212/WNL.0b013e31826e25aa

Spiegelberg, H. (1981). *The Phenomenological Movement: A Historical Introduction*. (Vol. 2, 3rd ed., in collaboration with Karl Schuhmann). Dordrecht: Springer Academic.

Steffenburg, S., Gillberg, C., & Steffenburg, U. (1996). Psychiatric disorders in children and adolescents with mental retardation and active epilepsy. *Archives of Neurology, 53,* 904-912. doi:10.1001/archneur.1996.00550090114017

Stevanovic, D., Jancic, J., & Lakic, A. (2011). The impact of depression and anxiety disorder symptoms on the health related quality of life in children and adolescents with epilepsy. *Epilepsia, 52,* e75-e78. https://doi.org/10.1111/j.1528-1167.2011.03133.x

Stuckey, H. L. (2013). Three types of interviews: Qualitative research methods in social health. *Journal of Social Health and Diabetes*, *1*(02), 056-059. https://doi.org/10.4103/2321-0656.115294

Sturniolo, M.G., & Galletti, F. (1994). Idiopathic epilepsy and school achievement. *Archives of disease in childhood, 70,* 424-428. https://doi.org/10.1136/adc.70.5.424

Symonds, J. D., Elliott, K. S., Shetty, J., Armstrong, M., Brunklaus, A., Cutcutache, I., ... & Zuberi, S. M. (2021). Early childhood epilepsies: epidemiology, classification, aetiology, and socio-economic determinants. *Brain*, *144*(9), 2879-2891. https://doi.org/10.1093/brain/awab162

Tanriverdi, M., Mutluay, F.K., Tarakci, D., Guler, S., & Iscan, A. (2016). The impact of epilepsy on preschool children and their families. *Epilepsy & Behavior, 62,* 6-11. https://doi.org/10.1016/j.yebeh.2016.04.045

Taylor, J., Jacoby, A., Baker, G.A., & Marson, A.G. (2011). Self-reported and parent-reported quality of life of children and adolescents with new-onset epilepsy. *Epilepsia, 52,* 1489-1498. https://doi.org/10.1111/j.1528-1167.2011.03094.x

Terry, D., Patel, A. D., Cohen, D. M., Scherzer, D., & Kline, J. (2016). Barriers to seizure management in schools: perceptions of school nurses. *Journal of Child Neurology*, *31*(14), 1602-1606. https://doi.org/10.1177/0883073816666738

Thomas, S.V., & Bindu, V.B. (1999). Psychosocial and economic problems of parents of children with epilepsy. *Seizure, 8,* 66-69. http://doi.org/10.1053/seiz.1998.0241

Thome-Souza, S., Kuczynski, E., Assumpcao Jr, F., Rzezak, P., Fuentes, D., Fiore, L., & Valente, K.D. (2004). Which factors may play a pivotal role on determining the type of psychiatric disorder in children and adolescents with epilepsy. *Epilepsy & Behavior, 5,* 988-994. https://doi.org/10.1016/j.yebeh.2004.09.001

Thompson, R., Kerr, M., Glynn, M., & Linehan, C. (2014). Caring for a family member with intellectual disability and epilepsy: Practical, social and emotional perspectives. *Seizure, 23,* 856-863. https://doi.org/10.1016/j.seizure.2014.07.005

Thompson, P.J., & Upton, D. (1992). The impact of chronic epilepsy on the family. *Seizure, 1,* 43-48. https://doi.org/10.1016/1059-1311(92)90054-5

Turky, A., Beavis, J.M., Thapar, A.K., & Kerr, M.P. (2008). Psychopathology in children and adolescents with epilepsy: An investigation of predictive variables. *Epilepsy & Behavior, 12,* 136-144. https://doi.org/10.1016/j.yebeh.2007.08.003

Ulate-Campos, A., & Fernandez, I.S. (2017). Cognitive and behavioral comorbidities: An unwanted effect of antiepileptic drugs in children. *Seminars in pediatric neurology, 24,* 320-330. https://doi.org/10.1016/j.spen.2017.10.011

Van Campen, J.S., Jansen, F.E., Steinbusch, L.C., Joels, M., & Braun, K.P.J. (2012). Stress sensitivity of childhood epilepsy is related to experienced negative life events. *Epilepsia, 53,* 1554-1562. https://doi.org/10.1111/j.1528-1167.2012.03566.x

Van Rijckevorsel, K. (2006). Cognitive problems related to epilepsy syndromes, especially malignant epilepsies. *Seizure, 15,* 227-234. https://doi.org/10.1016/j.seizure.2006.02.019

Varley, J., Delanty, N., Normand, C., Coyne, I., McQuaid, L., Collins, C., ... & Fitzsimons, M. (2010). Epilepsy in Ireland: Towards the primary–tertiary care continuum. *Seizure*, *19*(1), 47-52. https://doi.org/10.1016/j.seizure.2009.11.002

Vega, C., Guo, J., Killory, B., Danielson, N., Vestal, M., Berman, R., … Spann, M.N. (2011). Symptoms of anxiety and depression in childhood absence epilepsy. *Epilepsia, 52,* e70-e74. https://doi.org/10.1111/j.1528-1167.2011.03119.x

Verrotti, A., Carrozzino, D., Milioni, M., Minna, M., & Fulcheri, M. (2014). Epilepsy and its main psychiatric comorbidities in adults and children. *Journal of the neurological sciences, 343,* 23-29. https://doi.org/10.1016/j.jns.2014.05.043

Vona, P., Siddarth, P., Sankar, R., & Caplan, R. (2009). Obstacles to mental health care in pediatric epilepsy: Insight from parents. *Epilepsy & Behavior, 14,* 360-366. https://doi.org/10.1016/j.yebeh.2008.11.014

Wallander, J.L., & Varni, J.W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. *Journal of child psychology and psychiatry, 39,* 29-46. https://doi.org/10.1017/S0021963097001741

Wagner, J.L., Smith, G., Ferguson, P.L., Horton, S., & Wilson, E. (2009). A hopelessness model of depressive symptoms in youth with epilepsy. *Journal of pediatric psychology, 34,* 89-96. https://doi.org/10.1093/jpepsy/jsn052

Wang, D. S., Jani, A. B., Sesay, M., Tai, C. G., Lee, D. K., Echt, K. V., ... & Master, V. A. (2015). Video-based educational tool improves patient comprehension of common prostate health terminology. *Cancer*, *121*(5), 733-740. https://doi.org/10.1002/cncr.29101

Warren, E., Hart, G., Winterbottom, J., Baker, G., Jacoby, A., Luker, K., & Chadwick, D. (1999). An evaluation of a Nurse Specialist/Case Manager intervention in the management of epilepsy. *Epilepsia, 40(3, Suppl.2),* 107.

Watanabe, N., Hunot, V., Omori, I. M., Churchill, R., & Furukawa, T. A. (2007). Psychotherapy for depression among children and adolescents: a systematic review. *Acta Psychiatrica Scandinavica*, *116*(2), 84-95. https://doi.org/10.1111/j.1600-0447.2007.01018.x

Wiebe, N., Fiest, K. M., Dykeman, J., Liu, X., Jette, N., Patten, S., & Wiebe, S. (2014). Patient satisfaction with care in epilepsy: how much do we know?. *Epilepsia*, *55*(3), 448-455. https://doi.org/10.1111/epi.12537

Weiss, M.G., Ramakrishna, J., & Somma, D. (2006). Health-related stigma: Rethinking concepts and interventions. *Psychology, health & medicine, 11,* 277-287. https://doi.org/10.1080/13548500600595053

Williams, F., McCafferty, A., Dunkley, C., & Kirkpatrick, M. (2018). A UK survey of the experience of service provision for children and young people with epilepsy. *Seizure*, *60*, 80-85. https://doi.org/10.1016/j.seizure.2018.06.007

Williams, J., Steel, C., Sharp, G.B., DelosReyes, E., Phillips, T., Bates, S., … Griebel, M.L. (2003). Anxiety in children with epilepsy. *Epilepsy & Behavior, 4,* 729-732. https://doi.org/10.1016/S1525-5050(03)00159-8

Williamson, A., & Hoggart, B. (2005). Pain: a review of three commonly used pain rating scales. *Journal of clinical nursing, 14*(7), 798-804. https://doi.org/10.1111/j.13652702.2005.01121.x

Wood, L.J., Sherman, E.M.S., Hamiwka, L.D., Blackman, M.A., & Wirrell, E.C. (2008). Depression, anxiety, and quality of life in siblings of children with intractable epilepsy. *Epilepsy & Behavior, 13,* 144-148. https://doi.org/10.1016/j.yebeh.2008.03.012

Wood, L.J., Sherman, E.M.S., Hamiwka, L.D., Blackman, M.A., & Wirrell, E.C. (2008). Maternal depression: The cost of caring for a child with intractable epilepsy. *Pediatric Neurology, 39,* 418-422. https://doi.org/10.1016/j.pediatrneurol.2008.08.007

World Health Organisation. (2009). *Epilepsy.* Retrieved from http://www.who.int/mediacentre/factsheets/fs999/en/index.html

Yang, L., Ji, J., Lu, Q., Tang, P., Jiang, Y., Yang, H., & Tang, W. (2023). Caregivers' experiences in the management of children with epilepsy: a systematic synthesis of qualitative studies. *Seizure: European Journal of Epilepsy*, *106*, 117-128. https://doi.org/10.1016/j.seizure.2023.02.004

Yardley, L., & Marks, D. F. (2003). Research methods for clinical and health psychology.

Young Epilepsy. (2019). *Causes of epilepsy.* Retrieved from https://www.youngepilepsy.org.uk/about-epilepsy/causes-of-epilepsy/

Zainy, L. E., Atteyah, D. M., Aldisi, W. M., Abdulkarim, H. A., Alhelo, R. F., Alhelali, H. A., & Jan, M. M. (2013). Parents' knowledge and attitudes toward children with epilepsy. *Neurosciences Journal*, *18*(4), 345-348.

Appendices

Appendix 1: Questionnaire

Parent/ Guardian information:

1. Sex (please circle) : Male or Female

2. Date of birth:

3. Please indicate your qualifications (post-16 education):

Qualification	Number of years to complete	Full or Part time

4. How would you describe your ethnicity?

Child information:

5. Sex (please circle) : Male or Female

6. Date of birth:

7. At what age did the epilepsy begin? (e.g. when was the first recognized seizure?)

8. a. When was the last recognised seizure?

b. (If within the last six months) How frequent are the seizures? (please circle)

Daily Weekly Monthly Less than monthly

9. Does your child go to a mainstream school? (please circle) Yes No

a. **If yes**- Do they receive any additional support?

b. **If no**- Do they go to a specialist school?

10. Do they have an additional diagnosis of another condition (such as ADHD, Autism or Dyslexia, Asthma)? If yes, please note them below.

11. Apart from your GP and the epilepsy service, does your child access any other specialist services? (if yes, please indicate which services).

12. Have you always been under the care of the same epilepsy service (in the same geographic area)? (If you have moved house to another area at some point since diagnosis and changed services please indicate this below).

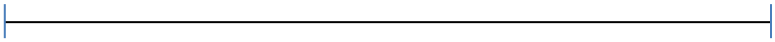
We are interested in your experiences with the doctors and nurses involved in the management/treatment of your child's seizure condition.

Please respond to each of the following 9 questions with the response that best describes how you feel by marking on the line ("Hardly" at one end and "Fully" at the other):

1. The doctors/nurses clearly explained the seizure condition to us.

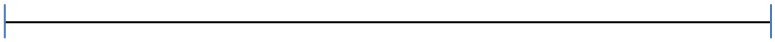
Hardly Fully

2. The doctors/nurses described how the medicine worked, and possible side effects of the medicine prescribed.



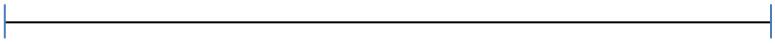
Hardly Fully

3. The doctors/nurses described any problems from the medicine that would need to be reported immediately.



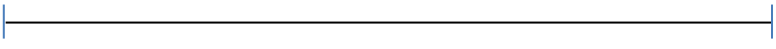
Hardly Fully

4. The doctors/nurses described how to give the medication.



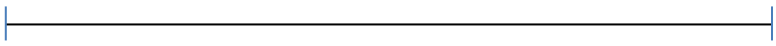
Hardly Fully

5. The doctors/nurses gave us an opportunity to ask questions about the seizures.



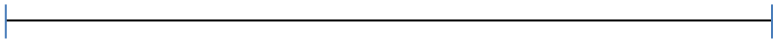
Hardly Fully

6. The doctors/nurses clearly explained what to do in the event of a future seizure.



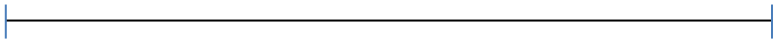
Hardly Fully

7. The doctors/nurses addressed our concerns and fears about seizures.



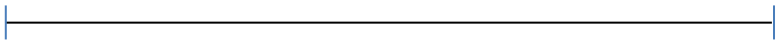
Hardly Fully

8. The doctors/nurses explained how to handle the seizures at school.



Hardly Fully

9. If I have a question outside of clinic, I can contact the doctors/nurses to get answers.



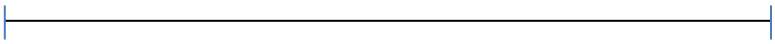
Hardly Fully

We also are interested in the areas where you desire more information about your child's seizure condition, or need more help in handling the seizures at this time.

Please respond to each of these 14 statements by marking the following scale ("Not at all" and one end and "A great deal" at the other):

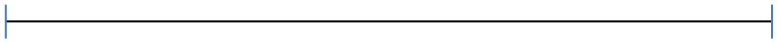
At this time how much do you need...

1. Information about the seizures.



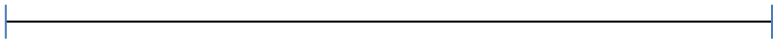
Not at all A great deal

2. Information about treatments of seizures.



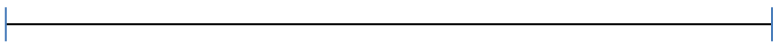
Not at all A great deal

3. Information about possible causes of seizures.



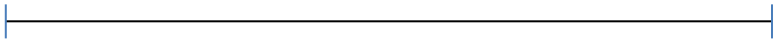
Not at all A great deal

4. Information about handling future seizures.



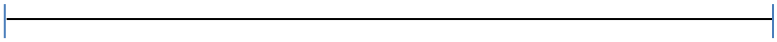
Not at all A great deal

5. Information about any activity restrictions.



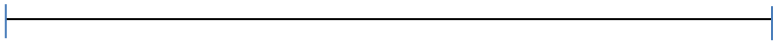
Not at all A great deal

6. Information about protecting your child from injury.



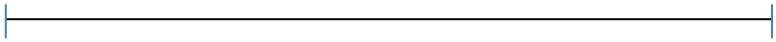
Not at all A great deal

7. Encouragement and support.



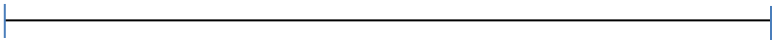
Not at all A great deal

8. Help in handling responses of others (school personnel, friends, child's peers).



Not at all A great deal

9. To discuss you concerns and fears about your child's future.

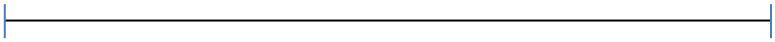


Not at all A great deal

10. To discuss fears about your child's seizures.

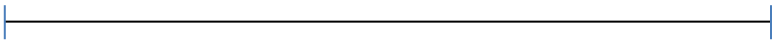
Not at all A great deal

11. To discuss concerns about your child's mental health and/or behavior.



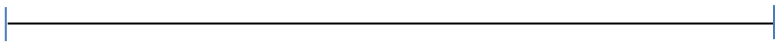
Not at all A great deal

12. Help with handling your child's response to seizures.



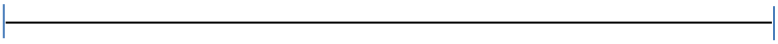
Not at all A great deal

13. For your child to discuss his/her concerns and fears about seizures with other children who have seizures.



Not at all A great deal

14. For your child to receive counseling about the seizures.



Not at all A great deal

Thank you for completing this questionnaire.
Please return in the pre-paid envelope provided.

Appendix 2: Cover letter

[Relevant NHS trust logo & University letterhead]

16/10/14 *Version 2*

Carer perspectives of paediatric epilepsy support services.

Dear parent/guardian,

I am writing to you about a research study being conducted by the Children's and young person's epilepsy care team at (insert name of relevant NHS trust), in collaboration with a research team at Lancaster University, to see if you would be interested in taking part. The project is about carer experiences of support services for paediatric epilepsy, and we hope the information gained will help us to better understand the needs of families who have a child with epilepsy.

Participating in the study may involve three parts; a questionnaire, an interview and the recording of a consultation with your paediatrician with a special interest in epilepsy. These are done at different time points, when it is convenient for you. If you do not feel comfortable with any aspect of the study you can choose to opt in/out of any of the three components at any point (please see consent form for details). Participation is purely voluntary, and you can withdraw from the research at any time, without need for explanation.

We have included an information sheet that gives a much more detailed description of our study and explains what will happen with the information collected. We understand the importance of keeping all information strictly confidential and information will only be shared between the small number of team members that have received approval to access it.

It is hoped you will find this study interesting and would like to take part. Please call us if you have any further questions about the study (see choice of contact numbers on the information sheet). If you would like to take part please sign and return the consent form in the envelope provided and we will contact you to make arrangements. We have included a copy of these forms for you to keep for your records. We would be unable to do any research without the generous participation of volunteers, so we really appreciate any help you can offer. ***Please note, there is no link whatsoever between this research and any treatment you receive, and you are under no obligation at all to participate.***

Yours sincerely,

Appendix 3: Full table of codes located under themes

Name	Description
A. Functions of the Epilepsy Service	
Accessibility	
Advice & information	Examples of any help, advice, guidance or information given with regards to the condition, side effects of medication or general problems that the parent encounters that is related to the condition or medication.
Availability	
Emotional Support	
ESN influence in consultation appointments	Examples of the work that has been done outside of clinic or the influence the ESN has had in directly informing the consultant e.g. advising of changes, significant events, detailing current circumstances of the patient since the last appointment, etc.
Managing behaviour	
Needs of CWE	
Effect of Epilepsy on Child	Any effects of condition on the child (changes in the child since symptoms began and subsequent diagnosis) e.g. learning, concentration, behaviour, social changes (friendship groups or ability to maintain relationships), confidence and child's understanding of condition where appropriate.
Child's understanding of condition	Child's understanding of condition including discussion the child has had with parents and what they have told the child about Epilepsy.
Effect of seizures	Behaviours displayed or feelings expressed by child in direct response to suffering from seizures.
Friendships	Any direct impact of the Epilepsy on the child's ability to make and/or maintain friendships or engage with social groups. This is for children without a diagnosis of Autism.

Information given to child	Information child has received in verbal or written format from either doctors or other Epilepsy service professional.
Restriction or not of activities, etc. due to Ep	Any mention of parent either restricting or specifically not restricting activities of the child due to their condition.
Self-esteem & confidence	
Transition to adult services	
Practical support	
Practical support & training	
Support & training with medication	
Additional support (outside Ep service)	Experiences of access to support outside of Epilepsy service e.g. groups, online support, helplines, etc. or where parent has not accessed any additional support services.
Co-morbidities	Discussion of any co-morbidities
ADHD	
Autism	
Cerebral Palsy	
Co-ordination issues	Not necessarily a co-morbidity but this relates to possible Epilepsy related issues with co-ordination which could have knock on affects e.g. school work, inclusion in sports, etc.
Epilepsy syndromes & genetic conditions	
Learning difficulties	
Memory & Concentration	Any significant changes in memory and concentration since diagnosis.
Diagnosis- Problems and process of diagnosis prior to consultant referral	Issues surrounding diagnosis when patient first presents with symptoms including first visits to A&E and/or GP. This includes all their experiences prior to being referred to a consultant.
A&E visits pre-Ep	Experience of A&E services prior to diagnosis of Epilepsy
Test performed prior to diagnosis	Experience to tests performed prior to diagnosis.

GP visits pre-Ep	Experience of GP services prior to diagnosis of Epilepsy
Parents feelings prior to diagnosis	Feelings expressed by parents prior to diagnosis.
Effect on Family	The effect of the Epilepsy on the family in terms of day to day life, socially; trips, outings & holidays, siblings, other family members e.g. Grandparents, Aunts & Uncles, etc.
Effect on parents	Any additional comments regarding the general effect of the condition on the parent(s) that aren't covered within the other nodes.
Effect on siblings	Any examples of how the sibling(s) have been affected by the condition e.g. effect of witnessing seizures, changes to family life, imbalance of attention from parents, their own fears and concerns, etc.
Effect on social life of parents	Any discussion of changes the parents have made to their social lives due to the Epilepsy e.g. not going out with friends or each other due to fears of leaving the child or losing the desire to go out as a consequence of the things they have been through (possible links to low mood/depression in the parent or continuation of restriction of activities but for themselves).
Trips, Holidays, Days out & regular activities (e.g. clubs, sports)	How the Epilepsy has affected their family with regards to holidays and outings. The change (if any) from before diagnosis to now and any restrictions or precautions they now have to take to ensure their child's safety and how that affects the wider family e.g. siblings including regular activities
Emotional & social support for parent (from friends & family)	Any discussion relating to support access from friends or family in relation to be able to cope better with the Epilepsy. Also includes where they may not have been so supportive.

Employer & issues with working	Any discussion relating to employment and allowances made at work e.g. taking time off, changes in hours, etc.
Expectations & concerns for the future	
Experience of acting ESN	Description of any experience with nurses or other professions who have acted in an ESN capacity without technically being employed to the role or having official training or expertise. These are mainly community nurses.
Experience of Consultants	Experience of paediatric consultants that were assigned to treat & (possibly) diagnose the child with Epilepsy including; experience of general consultation appointments, first meeting, explanation of condition, treatment/medication, and help & support offered. Mainly focuses on the main paediatrician but also includes any other consultants at a secondary level that they may have seen.
Accessibility & availability	
Consistency of care	Consistency (or inconsistency) of care at a consultant level. Also includes consistency of care due to arrangements made by the consultant e.g. open access arrangements for children's ward
Diagnosis	
Discussion of child's future	Any discussions about what may or may not happen in the future with regards to the child's Epilepsy.
Discussion of co-morbidities	Any mention of co-morbidities during consultations or examples where they are not discussed e.g. they weren't mentioned early on but were addressed later once child presented with symptoms.
Explanation & information about medication	Accounts of discussions between themselves and the consultant about the medication prescribed, how to administer it and any side effects.
Explanation of condition	
Relationship with consultant	Any mention of opinions (positive or negative) as to what they feel their relationship is like with the consultant.
Child's relationship with consultant	

Treatment & care plan (ongoing)	Discussion of seizures, medication and care plan for school/nursery in terms of ongoing treatment. Also any instances where parents are unsure of the care plan or procedure to follow if certain things were to happen.
Written Information provided	
Experience of Epilepsy care outside team post-diagnosis	Any experiences with medical professionals (e.g. hospitalisation, A&E admittance) for seizures or Epilepsy related care post-diagnosis where other professionals outside the Epilepsy team have treated the child.
Experience of ESNs	
Experiences in school or nursery	Anything relating to the parents' experience of Epilepsy within an educational setting (including school; mainstream or special and private/public nurseries prior to child being of school age). Also includes transport to & from school and care received by the "taxi" drivers.
Educational support in school	
Mainstream vs Special School	Any issues or discussion around decisions between mainstream & special schools &/or any changes that have been made during course of child's education.
Over-cautious due to the Epilepsy	Instances of the school or nursery being over-cautious with the child due to their Epilepsy e.g. phoning to make parents aware of things that they wouldn't call about if the child didn't have Epilepsy or treating them differently to other children when they don't need to or having been instructed to. (Possibly linked to lack of proper understanding of the condition).
Response to seizures	Any mention of how school have dealt with seizures of mention of their knowledge of what they would do if it were to happen.
Suggestion of co-morbidities	Any situation where the school i.e. teachers, support staff, have commented on child having possible additional needs that need to be investigated or occurrences of referrals made by school. This relates to possible co-morbidities that haven't been picked up on by the parent or consultant in the first instance.
Training not by ESN	
General comments or experiences of the Epilepsy Service	

Negative comments	
Positive comments	
Suggestions or ideas for improvement	
Medical mistakes and or complaints	Instances of missed diagnosis, wrong medication/dosage prescribed and medical mistakes or occasions where parents have made complaints about their child's care/treatment, etc.
Medication management	Issues relating to Epilepsy medication including training & administering of rescue medication.
Rescue medication	
Most difficult things about Epilepsy	Parent identifies specific things that they have found the most difficult about the whole experience of their child having Epilepsy.
Parent management of condition	How they as a parent manage the condition including expression of feelings such as fear or confidence, etc.
Parental understanding of condition	Where parent demonstrated understanding of the condition, co-morbidities associated with Epilepsy or researched information. Also where parent communicates a lack of knowledge or need for more information.
Parents' feelings post-diagnosis	Any strong feelings or opinions expressed by parents after their child had been diagnosed which relate to the other nodes they have been coded within.
Social attitudes or Stigma (inc. discrimination)	Social attitudes or views expressed by others (friends, relatives, strangers) that relate to the negative stigma attached to Epilepsy or any instance of discrimination against the child due to their Epilepsy.

Note. Highlighted codes were used for the themes in chapter 6.