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**Children's Experiences of and Involvement in the Treatment
and Management of their Epilepsy: A Qualitative Study**

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Doctor of Philosophy Child Life and Health

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2018

Declaration

I hereby declare that:

- This thesis has been composed solely by myself.
- The work presented in this thesis is my own.
- This work has not been submitted for any other degree or professional qualification.

Rebecca Elizabeth Parry Black

January 2018

Abstract

Epilepsy is one of the most frequently diagnosed neurological disorders in childhood (Roberts and Whiting-MacKinnon, 2012). A diagnosis of childhood epilepsy holds a variety of implications for the child and their parents beyond seizures (Ronen et al, 2010), including intricate and multidimensional treatment and management protocols (Kerr et al, 2011). However, despite the increasing recognition of the importance of listening to and consulting with children regarding their healthcare (e.g. Children and Young People (Scotland) 2014), children's accounts of their epilepsy and involvement in their treatment and management of the condition remain under examined (Harden et al, 2016).

This thesis is based on research and data collected with 23 children (aged 7-14 years) with epilepsy and 31 of their parents (54 participants in total). The research examined the everyday experiences of children with epilepsy and their involvement in the management and treatment of their condition at home and in a clinical setting. Children with a diagnosis of active epilepsy and one or both of their parents were interviewed separately on two occasions. Between the first and second interviews, an observation of a routine clinical appointment was conducted which guided the second interview and generated a more in-depth discussion. Additional research tools were used in both child interviews to further facilitate discussions. The data were analysed using a thematic approach.

The data indicate that children's understandings and meanings of epilepsy were drawn directly from their own experiences of the condition and by the information provided by their parents. Both children and parents considered the latter as gatekeepers of epilepsy knowledge. Parents detailed their control of how and what children understood by their condition, and ultimately how it became incorporated into part of their lives. The meanings of epilepsy crafted by children were influential in their experience of its treatment and management.

Children's involvement (at home and in the clinic) was widely reported as being valuable to children, parents, and healthcare professionals. There was, though, variability in how much involvement children sought with their care, illustrated through their various enactments of agency. Connected to this, parents' and

healthcare professionals' recognition and fostering (implicit and explicit) of children's agentic contributions and potential also varied across the sample and according to the circumstance shaping children's involvement in their care. Certain situations were illustrated as influential in children's desires for involvement and their abilities to demonstrate agentic capabilities. Additionally, the significant contribution parents have in supporting and promoting children's agentic capacity has been shown. Through exploring the data, I have illustrated children's agency and competence in their involvement in epilepsy care.

The thesis findings are contextualised through discussions of the sociology of childhood health and illness and provide further thought on the concepts of care and agency from a child's perspective. Additionally, the findings offer practical insights for healthcare professionals working with children with epilepsy. In sum, through scrutinising children's own accounts this research has illustrated how children with epilepsy enact agency through their involvement or resistance in epilepsy care, and how parents and healthcare professionals provide a mediating influence on this. As such it furthers sociological and clinical discussions on, and highlights, children's contributions to their care in the context of childhood epilepsy.

Lay Summary

Childhood epilepsy is a condition that affects the brain. When someone has epilepsy, it means they have a tendency to have epileptic seizures. Childhood epilepsy is one of the most common serious neurological conditions that can be diagnosed in children. Being diagnosed with childhood epilepsy holds a variety of issues for children and their parents beyond seizures, including complicated treatment and management protocols.

There has been an increasing drive to listen to and involve children in conversations and decisions about their health, particularly when they have a chronic illness such as epilepsy. However, there has only been a small amount of research exploring children's experiences of their epilepsy and to what extent they are involved in their treatment and management.

This research is based on interviews carried out with 23 children (aged 7-14 years) with epilepsy and 31 of their parents (54 participants in total). The research looked at the everyday experiences of children with epilepsy and their involvement in the management and treatment of their condition at home and in a hospital appointment. Children with epilepsy and one or both of their parents were interviewed separately on two occasions. Between the first and second interviews, I observed a routine hospital appointment and I talked to the children and parents about this in the second interview.

The research has shown that children's understanding of epilepsy was based on their own experiences of epilepsy (e.g. taking medication and having seizures) and the information provided by their parents. Children said that parents were greatly knowledgeable about epilepsy and were their primary source of information. Parents also spoke about how they managed what children understood by their condition, and ultimately how it fitted into their lives. Children's understandings of epilepsy influenced their experience of its treatment and management.

Further findings have shown how children are involved in their epilepsy treatment and management at home and in a hospital appointment. Most children spoke about being involved in taking their medication, keeping themselves safe in case of seizures,

and talking to doctors and nurses. Some children however spoke about not wanting to be involved in their treatment or management. Children's involvement can depend on what parents and healthcare professionals think and feel about children being involved and whether they notice that children want to be more involved. Children also said that certain situations made them feel that they might want to be less involved, for example, when visiting the hospital.

The findings from this research show how important, and possible, it is to speak directly with children about living with epilepsy in order to hear their views and to understand what it is like for them. Also, it shows that parents and healthcare professionals can influence children's experiences, understanding, and involvement in the treatment and management of their condition. The findings can offer children, parents', and healthcare professionals', practical insights in to managing childhood epilepsy.

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and tiredness, and through it all you have willingly sustained the belief that I could succeed. I could do it.

Words cannot quite express my gratitude to you all, thank you.

I began to realise how important it was to be an enthusiast in life if you are interested in something, no matter what it is, go for it full speed embrace it with both arms, hug it, love it and above all become passionate about it. Lukewarm is no good. Hot is no good either. White hot and passionate is the only thing to be.

- Roald Dahl

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Chapter One: Introduction

1. Setting the Scene

This thesis explores children's experiences of living with childhood epilepsy and their involvement in its associated treatment and management regimes. Childhood epilepsy is a complex chronic condition which in terms of its clinical presentation and aetiology, although still not fully understood, is well researched (Geerts et al, 2010). Connectedly, there is a wealth of literature regarding the clinical and neuropsychological outcomes of childhood, or paediatric, epilepsy. Yet, despite this there is very little research carried out on children's own experiences of childhood epilepsy or how they, themselves, are involved in their own epilepsy-related treatment and management (Harden et al, 2016). This leaves a significant gap in the literature and will, therefore, have implications for clinical practice. As Boyden and colleagues (1998) state, it is "only by hearing from children themselves is it possible to learn about their particular childhood experiences" (pp.170). It is essential, and a primary aim of this thesis, therefore to engage children in research surrounding their experiences of childhood epilepsy, as well as understanding and appreciating their involvement in its treatment and management. In addition, a secondary aim of the thesis is to understand how parents account for and contribute to the shaping of children's experiences of epilepsy. Moreover, a commissioned outcome of the study was to provide reflections and insights for clinical practice regarding children's involvement in their treatment and management.

This introductory chapter will detail the overarching aims and purpose of the research as a means of setting the scene and contextualising the thesis. Firstly, a clinical overview of childhood epilepsy will be given, detailing the aetiology, presentation (namely, seizures) and the treatment and management approaches for the condition. After which, a brief examination of the existing research and literature exploring childhood epilepsy will be detailed to contextualise the aims of the current research. In addition, legislation and healthcare policy will be drawn on to reinforce the value of these aims in the context of practical insights. Initially, a brief overview of the aims and methodological approach adopted will be presented, before providing an overview of the thesis structure.

2. Childhood Epilepsy

2.1 Clinical Overview

Epilepsy is one of the most frequently diagnosed neurological disorders in childhood (Roberts and Whiting-MacKinnon, 2012). Around one in 240 children in the UK have a diagnosis of epilepsy (Epilepsy Action, 2017), with the majority of such diagnoses being made in young children before the age of five (Appleton and Marson, 2009). A diagnosis of epilepsy is characterised by an enduring disposition to epileptic seizures and associated neurobiological, cognitive, psychological, and social features and corollaries (Fisher et al, 2014; Kerr et al, 2011). It is often termed 'epilepsies' representing its multiple potential presentations and associated complexity in treatment and management (Scheffer et al, 2017).

The many presentations of epilepsy can manifest with different types of epileptic seizures. These are usually divided into generalised and focal seizures; representing the areas of the brain the seizure originates from (Fisher et al, 2017a). Generalised onset, affects both sides of the brain from the start and include absences, tonic-clonic, and myoclonic seizure types; whereas focal onset affects one side of the brain and include focal aware and impaired awareness seizures. Additionally, seizures can have an unknown onset. This means that where the seizure begins is not clear. Each seizure type (irrespective of onset) displays different characteristics and visually can appear different due to the different regions of the brain involved with some more notable in their presentation than others (e.g. motor or non-motor symptoms). The table (one) below describes the variety of characteristics for each of the main types of seizure, illustrating the breadth and diversity of epilepsy and its presentations:

Seizure Type	Characteristics
Generalised Onset	
Absence Seizures	The individual becomes unconscious and unresponsive for a few seconds and appears to be daydreaming or 'switching off', eyelids flutter, slight jerking movements of the body or limbs. Typically, absence seizures last 2-3 seconds, and can occur in clusters with

	some having hundreds in a day. Individuals return to what they were doing beforehand afterwards with only a slight disruption.
Tonic-Clonic Seizures	The 'tonic' phase, is often manifested by an individual losing consciousness, falling to the floor, muscles stiffen, and crying out. The 'clonic' phase follows with limbs jerking, loss of control of their bladder and/or bowels and difficulty breathing. Most tonic-clonic seizures last between 1-3 minutes with individuals often experiencing a headache, feeling sore, confusion, and feeling the need to sleep afterwards.
Focal and or Generalised Onset	
Tonic Seizures	When all parts of the brain are involved (generalised) all muscles tighten and the whole body goes stiff. The individual may fall to the floor, their eyes open wide and roll upwards, arms may rise and legs stretch or contract. They may cry out and stop breathing during the seizure. When only part of the brain is involved, muscles tighten in just one area of the body. Tonic seizures usually last less than 60 seconds. Once they are over, the muscles relax, leaving the individual feeling tired.
Atonic Seizures	The muscles often go limp and individuals can drop to the floor resulting in injuries to the head, nose, or face. Atonic seizures are very brief, usually lasting just 1-2 seconds with muscle tone returning when the seizure is over.
Myoclonic Seizures (or myoclonic jerks)	Too short to affect consciousness myoclonic jerks are sudden but can be mild, like a twitch, or forceful resulting in the individual falling over or throwing anything they may be holding. Myoclonic seizures usually only last for a fraction of a second however, some can have clusters of several seizures over a short time period.
Focal Onset	

<p>Focal Aware / Impaired Awareness Seizure</p>	<p>What happens during a focal seizure depends on which part of the brain the seizure happens in, as different areas of the brain control movements, body functions, feelings, and reactions. Some individuals experience just one symptom, while others experience several, also some can stay fully conscious of what is happening, even if they cannot talk or respond (focal aware) and others can lose awareness (focal impaired awareness). Most focal seizures are brief, lasting between a few seconds (aware) and 2 minutes (impaired awareness). Individuals might feel fine afterwards and return to what they were doing straight away, or they might feel confused or tired.</p> <p>Motor symptoms of focal seizures may include: part of the body going stiff; jerking; the head and eyes turning to one side; lip smacking, repeated swallowing or chewing; repeated movements; running or walking. Whereas, non-motor symptoms include: feelings of fear, anxiety, anger or pleasure; changes to vision, hearing, smell or taste; having sensations of being hot or cold; hallucinations; changes to breathing, heart-rate or skin tone; or, difficulty processing language.</p>
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Table One: Description of Seizure Types (derived from: Epilepsy Action (2017), Fisher et al (2017a) and Fisher et al (2017b)).

Certain clusters of seizure types, signs, and characteristics can produce recognisable patterns: a type of epilepsy syndrome. Identifying or diagnosing an epilepsy syndrome allows more effective treatments to be prescribed and offers more useful information on the prognosis of a patient's epilepsy. However, a specific epilepsy syndrome will only be identified or diagnosed in 60-70 percent of children with epilepsy (Fisher et al, 2017a). There are over 30 (and counting) different childhood epilepsy syndromes (Epilepsy Action, 2017).

2.2 Diagnosis and Prognosis

With a multitude of different seizure types and syndromes classified under the single label of 'epilepsy', achieving a complete and accurate diagnosis can be challenging,

even more so in young children (Nordli, 2002). A classification system by International League Against Epilepsy (ILAE; most recently revised in 2017), is an international tool used for diagnosing epilepsy and has multiple components and levels to identify precisely the aetiology, type of epilepsy, and to improve the prediction of prognosis (Fisher et al, 2017a). To begin the diagnostic process, a child must be identified as having epileptic seizures (as detailed above). After the identification of seizure type, the type of epilepsy can be ascertained from the groupings: focal, generalised, combined generalised and focal, or an 'unknown' epilepsy grouping (Scheffer et al, 2017; Fisher et al, 2017a). The third and final level of diagnosis is that of epilepsy syndrome, where a specific syndromic diagnosis can be made (Scheffer et al, 2017). The classification tool details that where possible, a diagnosis at all three levels should be sought in conjunction with determining the aetiology of the epilepsy. These are however not always achieved (Scheffer et al, 2017). The process of diagnosis is thus complicated. It is especially challenging to achieve in a paediatric setting, with infants' and children's symptoms often presenting with minimal clarity and consistency (cf. adult patients) (Nordli, 2002; Appleton and Marsh, 2009).

Further complexity in diagnosis is added by there being no definitive or objective diagnostic tests for the condition (Alarcón, 2012). There are no biomarkers or self-complete screening tool that can indicate for certainty the presence of epilepsy (Alarcón, 2012). Only an accurate, detailed medical history and the witnessing (either visually or via medical tests) of a 'seizure' can lead paediatric neurologists to suspect childhood epilepsy (Appleton and Marsh, 2009; Scheffer et al, 2017). The diagnosis itself comes from the interpretation of results from the battery of technological devices and procedures: electroencephalograms (EEGs); sleep deprived EEGs; video telemetry with EEGs; and, Magnetic Resonance Imaging (MRI) scans. Such technology acts as a proxy, allowing paediatric neurologists to observe un-seen brain activity and to conclude an epilepsy diagnosis, as well as offering insight into the potential aetiology of the epilepsy (Nordli, 2002).

For two thirds of children, there will be no known cause for their epilepsy (Appleton and Marson, 2009; Epilepsy Action, 2017). Evidence has identified some causes of epilepsy including: genetic factors, perinatal hypoxia, trauma at birth, infectious diseases, or acquired metabolic disease (Appleton and Marson, 2009). Around 70

percent of children's epilepsy will resolve in childhood, with the remainder however continuing into adulthood (Appleton and Marson, 2009; Alarcón, 2012).

2.3 Treatment and Management

For most children, epilepsy is controlled using anti-epileptic drugs (AEDs). These medications suppress seizure activity controlling the effects of the epilepsy, with approximately 70 percent of children with epilepsy able to control their seizures with AEDs (Epilepsy Action, 2017). There are numerous AEDs that can be prescribed for the differing types of epilepsy syndromes, all with a range of benefits and side effects (Appleton and Marson, 2009; Alarcón, 2012). Other treatment options include the ketogenic diet, and more invasive medical procedures such as brain surgery and vagus nerve stimulation (Appleton and Marsh, 2009). These alternative treatments are dependent on a child's aetiology and type of epilepsy, and may not be available or recommended to all. Such treatment approaches are typically used in children whose epilepsy is resistant to medication (Alarcón, 2012). The aim of all the treatments is to stop, or control, a child's seizures; there is no cure for epilepsy (Alarcón, 2012), though some children can 'grow' out of epilepsy as noted above (Appleton and Marsh, 2009; Alarcón, 2012)

Despite treatment, seizures can still occur requiring intricate and multidimensional management arrangements to be put in place. Such arrangements can include: constant supervision (particularly near roads or when swimming for example), detailed care plans in case of prolonged seizures, and detailed medication regimes can all be required for children with epilepsy. The management of childhood epilepsy can influence medical, psychological, social, and personal, dimensions of a child's life (Kerr et al, 2011). Epilepsy can have short- and long-term effects and implications for both children and their families and the involvement of a range of specialist healthcare professionals (Kerr et al, 2011; Alarcón, 2012). Consequently, a diagnosis of epilepsy holds a variety of implications for life beyond the physical effects associated with seizures (Camfield, 2007; Ronen et al, 2010). The primary goal in contemporary epilepsy management and treatment is to optimise the child's life in order to afford them a lifestyle as free as possible from the medical (and psychosocial) effects of their condition (Speechley et al, 2012).

2.4 Terminology

The ILAE provide an important source of guidance for healthcare professionals on epilepsy diagnosis and associated terminologies. Recently, the ILAE recommended that epilepsy be reclassified from a 'disorder' of the brain, to a 'disease' of the brain (Fisher et al, 2014). This shift has been met with a wealth of controversy, not least from patient, special interest and clinical groups (Noble et al, 2017a). In their mass survey of these interested (and vested) groups, Noble and colleagues found that the descriptor 'condition' was much preferred over 'disease', which nine out of ten respondents were against (2017a). Given the perceived distaste with this phrasing and the sociological connotations of the term 'disease' (Timmermans and Haas, 2008), I will refer to childhood epilepsy as a condition. Similarly, although the term 'epileptic' is still in use, it was felt by the same respondents to be equally inappropriate; I will instead use 'children with epilepsy', where appropriate (Noble et al, 2017b).

Throughout the thesis I will refer to epilepsy as the overarching condition, avoiding naming particular syndromes that may have been diagnosed to avoid confusion (not all children are diagnosed or aware of the type of epilepsy they have). Instead I will only discuss the variety of seizure experience as described by children and their parents, by means of children's own descriptions to define their seizures. For example, 'daydreams' for absence seizures, 'fits' for tonic-clonic seizures, and 'shakes' for myoclonic seizures. By using children's words and phrases, it ensures that the analysis and associated discussions remain rooted in their experiences, understandings, and conceptualisations of seizures and epilepsy more generally.

This section has provided a clinical overview of childhood epilepsy illustrating its complexity through the array of seizures and syndromes as well as the diagnosis process and prognosis for children with epilepsy. The various treatment options and management approaches adopted to accommodate the condition also offer an insight into the potential influence that having epilepsy can have on children and their parents' lives. The next section examines the sociological value of exploring childhood epilepsy and the previous focuses of research in the published literature to further contextualise the current research aims and methodology.

3. Contextualising the Study

Through detailing the clinical dimensions of defining, treating and managing childhood epilepsy, the sociological value of exploring children's experiences of living with the condition can be drawn out. Previous sociology of child health and illness research has focused on chronic conditions such as childhood diabetes, asthma, cancer and cystic fibrosis (e.g. Prout et al, 1999; Williams et al, 2014; Rankin et al, 2017). Childhood epilepsy has, however, received significantly less sociological exploration. With a complete diagnosis difficult to achieve and the sheer variety of potential presentations, types, and aetiologies, it can be challenging to untangle the social from the biomedical experiences of epilepsy. Compared to other childhood chronic illnesses, epilepsy can consequently appear to be more complicated to explore.

Similar to other chronic conditions, however, epilepsy is a broadly hidden condition. It can be only noticeable or identifiable through seizure activity, and to some extent the associated treatment regimes (e.g. doses of anti-epileptic medication). Yet, unlike other chronic conditions, when 'present' epilepsy has a unique and visible physical manifestation (i.e. seizures) and can appear in an unpredictable cycle of symptoms (i.e. seizure frequencies and intensities). Unpicking this further reveals multiple aspects interesting to explore sociologically: the contrast between the bodily reaction and the ambiguity of what happens when having a seizure; the paradox surrounding the visible/invisible nature of the condition and the abruptness with which this can change, and the societal (mis-)understandings of the condition.

Looking in more depth at these areas of sociological interest, a sense of unknowing, uncertainty, risk and vulnerability emerges regarding the physicality of seizures (Scambler, 2004). For the child (or adult) experiencing a seizure it can be filled with uncertainty and unknowing. Seizures can occur without children necessarily having the (conscious) awareness of experiencing the seizure. For example, absence seizures can be brief and fleeting in their manifestation, often going unnoticed by those having them. Similarly, when a tonic-clonic seizure occurs there can be a host of bodily movements, actions and reactions, yet a child could wake only feeling exhausted and sore. There is little awareness of exactly what happened to them or their bodies (as

noted in Table One; Appleton and Marsh, 2009). As a result, there can be a sense of unknowing in how they (and their bodies) experience epilepsy.

Compounding the unawareness of epilepsy is the suddenness with which seizures happen. Only a small proportion of those with epilepsy have auras (warning signs) or are able to detect triggers for their seizures, the majority are left unaware and uncertain as to when a seizure can happen. The uncertainty adds to the sense of vulnerability and risk surrounding epilepsy (Webster, 2017). The suddenness of symptoms and lack of perception is distinct from other conditions such as diabetes for example, where symptoms and signs from the body can be observed for an impending hypoglycaemic event (Montez and Karner, 2005). Individuals with diabetes can have a (bodily) awareness and sense of consciousness that 'something' is happening to their body and are then able to listen to their 'communicative body' and deal with the issue through injections of insulin for example (Montez and Karner, 2005). The epileptic body or the 'temporarily eventful body' has received minimal exploration of what this could mean for children and adults with epilepsy (Shilling, 2007; Coffey and Watson, 2014).

This unawareness of the experience of epilepsy and when it can present could have implications for how children come to understand and conceptualise their condition, how it influences their sense of self and identity (Harden et al, 2016). Also, how they and their parents seek to incorporate the condition in their daily lives, and manage the uncertainty and risks of seizures shapes children's conceptualisations. Furthermore, how a child understands and experiences epilepsy can influence how care associated with the condition is perceived and children's potential involvement within it.

Intersecting with this sense of unawareness and the contradictory and surprising physicality of seizures, is the paradox surrounding the visibility and invisibility of the condition. As noted, there are minimal external markers to indicate a diagnosis of epilepsy; no insulin pumps or inhalers marking diagnoses of diabetes or asthma respectively. In the periods between seizures it can be invisible allowing children with epilepsy to lead relatively normal lives and normal childhoods (Appleton and Marsh, 2009). However, when seizures do occur this normality can be disrupted, the condition becomes visible, changing with it how the child is viewed – suddenly, there is

something different about them, unusual (Scambler, 2004). This paradox of 'in/visibility' means that children can simultaneously be viewed as healthy, normal children, with an invisible, hidden condition. However, when a seizure occurs this paradox shifts suddenly – the epilepsy (or seizure) becomes visible and the child becomes invisible, subject to their uncontrolled body. These dynamics of 'in/visibility' could have a cumulative effect on how children integrate their epilepsy in to their lives, and how, as being diagnosed with the condition, influences how others view them and their childhood (Schiender and Conrad, 1983). What this means for children and their parents' in disclosing the epilepsy diagnosis, and their experiences and understandings of epilepsy highlights further areas of potential sociological exploration.

Furthermore, a question emerges on how the parent-child relationship is shaped by the presence of childhood epilepsy, the uncertainty and unawareness, the shifting paradox of 'in/visibility' and how this influences children's childhood in the face of (perceived) unknowing, vulnerability and risk. The altered child-parent relationship has potential implications for children's agency and autonomy and their childhood experiences. The exploration of such child-parent dynamics and children's agency, coupled with the unawareness and uncertainty of direct experiences of a condition such as epilepsy has yet to be fully examined.

This discussion is not to suggest, however, that epilepsy has not been researched through a sociological lens previously. Rather, two main threads of research have dominated the exploration of childhood epilepsy, and epilepsy more broadly: studies examining stigma and epilepsy (drawing on more sociological underpinnings), and quality of life studies (drawing on more clinical assessments of impact and influence). Most prevalently, in regards to sociological interest, has been the attraction to stigma. The overall low visibility as a condition and the uncertainty of when seizures could occur, have made it an enticing subject of exploration (Goffman, 1963; Coleman-Brown, 2016). It is understandable that the social management of (adulthood and childhood) epilepsy has been studied in great detail in the existing epilepsy literature (e.g. Scamber and Hopkins, 1986; Jacoby, 2008; Benson et al, 2015; Benson et al, 2017). As Schneider and Conrad (1983) stated: "the history of epilepsy is a history of stigma" (pp:29), emphasising the sociological interest in the condition has been surrounding the negative and pejorative conceptions of the condition.

The attention of the stigmatising nature of the condition has seemed to pervade and dominate, highlighting the consequences of the meanings of epilepsy and the implications it has on daily life. It has overshadowed the diverse and unique experiences that emerge when exploring individuals' accounts, experiences and views of their conditions. By focusing on the differences, or aspects that appear stigmatising, it has narrowed the focus to a negative and, frequently, externalised view of the condition. In persisting in this focus, I assert that how children and adults create their meanings, develop an embedded understanding of their epilepsy, and their involvement in their condition's treatment is overlooked. As well as projecting a persistent a negative reflection of the condition, it reinforces the negative components of the condition and the experiences. The focus on stigma thus obscures how meanings are shaped and the interplay they have with wider experiences, engagements and interpretations of the condition. Therefore, there is great scope in exploring more broadly children's meanings and experiences of their childhood epilepsy.

In attempting to examine wider and more holistic experiences of living with epilepsy, a further area of research interest has developed: the impact of epilepsy on quality of life. Quality of life is a multi-dimensional concept that brings together and explores an individual's circumstances, identity, lifestyle and experiences along with their own perceptions about themselves and their health (Roberts and Whiting, 2012). In particular, quality of life research has focused on physical and psychological wellbeing, and social and cognitive adaptation in daily life (Elliott et al, 2005; Roberts and Whiting, 2012). The relatively extensive body of research concerning quality of life and childhood epilepsy has demonstrated a detrimental effect on academic achievement, associated with poor behaviour management and performance, social isolation, and low self-esteem in children with the condition (Kerr et al, 2011; Rodenburg et al, 2011; Roberts and Whiting, 2012). Parents of children with epilepsy have also been shown to have higher rates of depression, anxiety, and stress, due to the additional concerns and care needs associated with having a child with a chronic illness (Kerr et al, 2011). Consequently, research has shown that children with epilepsy and their parents have a demonstrably poorer quality of life than families who do not live with childhood epilepsy (Bishop and Allen, 2003; Elliott et al, 2005; Roberts and Whiting, 2012). The findings from such quality of life studies have provided great insight into the impact of childhood epilepsy on children and their parents and have

offered ideas for improved service provision and care management interventions for families (Elliott et al, 2005; Talarska, 2007).

Despite this, measures assessing quality of life (and associated health related quality of life measures) have been heavily critiqued, both as measures and as attempts to explore childhood epilepsy (Taylor et al, 2008; Apers et al, 2013). Broadly, quality of life research has predominately been driven by a quantitative perspective with hypotheses and theoretical models confining responses to preformed frameworks (Apers et al, 2013). These preformed frameworks, it has been argued, could disproportionately emphasise health-related factors (over the effects of non-health related factors) affecting illness. And more fundamentally, are based on the assumption that the closer an individual's life mirrors a 'normal' life, the better their quality of life (Eiser and Moore, 2001; Moons et al, 2006; Armstrong et al, 2007). Moreover, the manner in which specific items are created, the restriction of choice, and the weighting system used, all comprise the accuracy and usefulness of the measures used (Eiser and Morse, 2001; Armstrong et al, 2007). Therefore, it can be argued that quality of life measures do not assess what constitutes 'quality of life', neither in general, nor for individuals, and does not necessarily reveal how their life is impacted by their chronic illness (Carr and Higginson, 2001; Moons et al, 2006).

In reflecting on quality of life studies examining childhood epilepsy explicitly, a number of researchers have raised supplementary concerns (Kerr et al, 2011). Such studies have maintained a singular focus on psychopathology, lack of adjustment, or comparisons with atypical populations, providing little investigation of opportunities for positive growth in the context of childhood illness (Barlow and Ellard, 2006). The negative stance adopted by these investigations frames childhood epilepsy as a sad and helpless tale of childhood chronic illness; this is not necessarily how it is viewed, or experienced, by children and their parents (Schneider and Conrad, 1983; Elliott et al, 2005). A positive stance and the promotion of positive outcomes and experiences are therefore worth considering in this and future research.

Furthermore, in choosing to examine children's perspectives, these measures of quality of life fail to access them appropriately or accurately (Armstrong and Caldwell, 2004). Many of the measures used with children originated from measures designed for use with adults and consequently use an adult-centric focus and theoretical basis (Elliott et al, 2005). Adapting these measures, instead of creating new age-specific

tools, fail to account for children and their age-related differences (Eiser and Morse, 2001; Moffat et al, 2009).

This adult-centric focus is further compounded as a large proportion of such epilepsy studies are typically based upon single proxy parental (or primary care-provider) reports (Gannoni and Shute, 2010; Harden et al, 2016). These are completed on behalf of the child, from the child's perspective, or alternatively from the reporters' perspective of the child's life (Sherifali and Pinelli, 2007; Gannoni and Shute, 2010). Whilst obtaining a parent perceived insight is valuable, it is also limited (Bower Baca et al, 2010). The over-reliance on, predominately maternal, reports yields findings limited to this single viewpoint which does not consider the child's own perspective on their quality of life (Wallander et al, 2003). A number of pragmatic reasons have been put forward for using proxy reporting measures (Shute, 2005) including, a paternalistic neglect of children's views and the assumption that children are incapable of accurately reporting on their lives (Garth and Aroni, 2003; Shute, 2005; Tisdall et al, 2009). These reasons are infrequently reported within studies presenting parental proxy measures as acceptable standard practice (McEwan et al, 2004; Harden et al, 2016).

Evidence indicates, however, that parents' and children's views often differ on such quality of life matters (Bower Baca et al, 2010). Hoare and colleagues (2000), for example, found no correlation between parent and child responses when they explored the differences and similarities between children's reported quality of life, and parent's reports on their child's quality of life, whilst living with either childhood epilepsy or diabetes. Further, Ronen and colleagues (2001) found that when children with epilepsy were questioned directly, they revealed meaningful and important issues pertaining to their quality of life that went beyond those already put forward by parents or healthcare professionals. For example, children's quests for normality were not usually known by parents and they were also not as concerned by the future as their parents (Ronen et al, 2001; Elliott et al, 2005). This disconnect in perceptions further highlights the existence of experiences that may not have been captured by studies utilising proxy reports (McNelis et al, 2007; Verhey et al, 2009; Vanstraten and Ng, 2012). Eiser and Morse (2001) similarly advocated that there are inevitable differences between adults and children in their understanding and experience of illness and health. By capturing both perspectives, a more descriptive and complex

understanding of the experiences of childhood epilepsy can be attained (Eiser and Morse, 2001).

In accordance with these findings, emerging literature has begun to stress the importance of obtaining children's views and accounts, re-addressing the misbelief that children are unreliable respondents (Elliott et al, 2005; Shute, 2005; Tisdall et al, 2009). In response, qualitatively-led research has therefore sought to include children in examining their health and illness (McEwan et al, 2004; Harden et al, 2016). Despite this, children's experiences of living with epilepsy have only been addressed directly in a small number of studies (see: McEwan et al, 2004; Moffat et al, 2009; Bower Baca et al, 2010; Harden et al, 2016).

The studies that have explored children's own experiences of epilepsy most commonly reported themes regarding the challenges and constraints of living with epilepsy (Harden et al, 2016). The quest for normalcy was frequently described by children, across the majority of these studies, manifesting through concerns of the impact of epilepsy on socialising, peer acceptance and worries regarding independence (Moffat et al, 2009; Hightower et al, 2002). In slight contrast, Lewis and Parsons (2008) found there was an implicit reluctance in children accepting epilepsy as 'part of them', with many self-reported feelings of secrecy, stigma, and shame, and researchers noting that there was a readiness to talk about feelings of difference in relation to others (Lewis and Parsons, 2008). Yet, many children were clear about the nature of their condition (including seizures), and understood its implications for their lives, suggesting a sense of different normality was created (Lewis and Parsons, 2008). More epilepsy-specific themes were also found regarding the adjustment, compliance and side effects of anti-epileptic medication, the experiences of having seizures (in front of others and in general), worries of what the future might bring in terms of prognosis, and the experiences of visiting a doctor (Moffat et al, 2009; Hightower et al, 2002). From the small collection of studies, it has been well illustrated that children are capable of discussing their experiences of epilepsy, in great depth and breadth, extending our understanding of childhood epilepsy's influence on children's lives (McEwan et al, 2004).

However, the limited research focusing on children's experiences of epilepsy has still yet to explore children's involvement in their own epilepsy-related care at home and

in clinical settings (Harden et al, 2016). References to the treatment and management regimes associated with epilepsy (e.g. daily medications and seizure safety procedures) have rarely been discussed in how they are negotiated and managed between children and their parents in the home. Studies exploring children's involvement in such regimes have tended to focus on other childhood chronic conditions such as asthma and diabetes and then only in young people typically over the age of 12, not children (Garth and Aroni, 2003). Such studies have sought to understand and establish young people's adherence to treatment regimes, self-management, and their preparation in transitioning to adulthood and adult healthcare services (Sawicki et al, 2015). These studies demonstrated young people's capacity and agentic potential in self-care and their involvement in treatment regimens in the home (Sanz, 2003; Rankin et al, 2017).

There remains minimal examination of children's experiences of involvement in their clinical care. Broad insights obtained from the small number of existing studies on specific illnesses or periods of hospitalisation, have shown children's limited participation in clinical discussions with their parents and healthcare professionals (Coyne, 2006a; 2006b; Kelly et al, 2012). Children's experiences of negotiating involvement in clinic appointments with parents and healthcare professionals, and their thoughts, willingness, and understandings of such participation has been overlooked (Garth and Aroni, 2003; Coyne, 2006a; Harden et al, 2016). Moreover, there is little insight into parents' responses to children's potential for involvement in these clinical situations, or within the home. Thus, there is a lack of insights into the clinical component of childhood epilepsy care and experience for children and parents (Harden et al, 2016).

This section has highlighted the areas of previous research interest and the insights it has created in understanding children's and parents' experiences of living with childhood epilepsy. The reliance of quality of life studies has provided a negative outlook on the outcomes of a diagnosis of childhood epilepsy, and the few qualitative based studies have provided an increased understanding of children's experiences. Yet, the little exploration of children's own experiences and involvement in the treatment and management of the condition, at home and in healthcare settings, means that a broad encompassed account of children's experiences have not been

obtained. The academic and clinical interest in children's involvement in treatment and management care and its importance will now be examined.

4. Children's Involvement

The importance of exploring children's perspectives and experiences has corresponded with the introduction of children's rights and more child-centred policies, as well as academic disciplines examining children and childhood (Tisdall et al, 2009; McNamee, 2016). The introduction and almost worldwide ratification of the United Nations Convention on the Rights of the Child (UNCRC, 1989) in 1989, posited three core principles of participation, protection, and provision (Freeman, 2009). These principles aimed at increasing advocacy and encouragement of children's participation in matters that affect their lives (UNICEF 2003; Freeman, 2009). Article 12 of the UNCRC (respect of the views of the child) is of particular interest in this context as it emphasises the importance of children being able to express their views freely and having them taken into consideration on matters that concern them, such as their own healthcare (UNCRC, 1989). Likewise, Article 3 (the best interests of the child) is also relevant in that the best interests of the child must be the primary concern in making decisions that affect them, further emphasising the need to involve children in their own healthcare decisions affecting them (UNCRC, 1989). Additionally, the ratification of the UNCRC by the UK government heightened awareness of children as an important minority group with rights and moral standing of their own (Freeman, 2009).

In a Scottish legal context, the Children and Young People (Scotland) Act 2014 further emphasises that children's opinions should be sought with regard to matters and or decisions concerning their welfare. Similarly, in the Scottish health care context, the Action Framework for Children and Young People, highlights that children experiencing ill-health have an active role through their participation in the planning and delivery of their care (Scottish Executive, 2007). Connectedly, guidelines published by the Royal College of Paediatrics and Child Health (RCPCH), emphasise children and young people's involvement in making their own healthcare choices and encouraging their confidence in interacting with healthcare professionals (RCPCH, 2014). Given the legislation, policy and guidelines produced, there has been wider recognition that children should be consulted, listened to, and their perspectives taken seriously

(Percy-Smith and Thomas, 2010; Coyne, 2006a; Soderback et al, 2011; Kelly et al, 2012). This reinforces the importance of researching children and their own experiences and involvement in their healthcare.

Despite these intentions, children continue to face challenges in being meaningfully and actively involved in decisions about their health care, particularly in clinical settings (Coyne, 2006a, 2006b; 2008; Soderback et al, 2011; Kelly et al, 2012). Similarly, the lack of insight into children's involvement in treatments and managements of childhood epilepsy presents a further shortfall in understanding that can be detrimental to their clinical care. Hightower and colleagues (2002) concluded in their study that the insight obtained through interviewing children, could assist healthcare professionals in establishing appropriate and comprehensive help packages to support children with epilepsy. Thus, obtaining such insights into children's experiences of involvement in treatment and management of their childhood epilepsy could offer a valuable awareness of whether children (as agentic actors) are being appropriately served by these legislative and policy directives.

5. Research Aims and Methodological Approach

Given the discussions from the previous sections, this research aims to gain broader insights of children's experiences of living with childhood epilepsy and their involvement in the treatment and management of their condition across both the home and clinical settings. In conjunction with this, how parents shape and support children's involvement in and across these setting will also be examined. These overarching aims were refined into three key research questions:

1. What does having epilepsy mean to children?
2. To what extent do children perceive themselves as actively involved in the management and treatment of their epilepsy within the home and clinical settings? In what ways do parents' shape and support children's involvement?
3. What are the support and information needs of children with epilepsy?

A complementary, commissioned, aspect to the study was to provide insights to epilepsy healthcare professionals to enhance clinical practice. To address these

research aims and questions, twenty-three children with active epilepsy (aged between 7 and 14 years) and thirty-one of their parents were recruited to this qualitative study. Children and parents were interviewed separately on two occasions. Between the first and second interviews, an observation of a routine epilepsy clinic appointment was conducted to guide the second interview and generate a more in-depth contextualised discussion. Additional research tools were used in both child interviews to further facilitate discussions. The interviews were audio recorded and then transcribed fully, and observation notes written up after the observed clinic appointments. The data were analysed using a thematic approach.

6. Thesis Structure

This introductory chapter (Chapter 1) has defined childhood epilepsy, alongside detailing its prognosis, diagnosis, presentation, treatment, and how it is managed. The clinical overview has been supplemented by examining the potential value of using a sociological lens to explore childhood epilepsy. The previous research interest surrounding stigma and quality of life has emphasised the negative experiences and highlighted the neglect of examining children's own experiences of their childhood epilepsy. Worldwide and local legislative and policy changes, from the last three decades, were drawn upon to further reflect on the view of children's involvement in their own healthcare and associated decisions and the value with doing so. These insights have served to broadly contextualise the key study aim: to explore children's own experiences of childhood epilepsy and their involvement in the treatment and management of it. The methodological approach of the study was also introduced.

The rest of the thesis is structured into eight chapters. Chapter 2 provides a review of the literature on the sociologies of childhood, family and care in the context of chronic illness and epilepsy. These literatures further assisted in the development of the research questions addressed in this study. In Chapter 3 the study's methodological approach will be discussed in-depth, alongside the research methods, participant details, data collection and analysis process, and ethical considerations of the research.

This will then be followed by four chapters presenting the findings of the research through three distinct but interconnected themes: understandings and meanings of

epilepsy (Chapter 4); experiences and involvement in treating and managing the condition (Chapter 5 and 6 respectively); and, finally, experiences and involvement in the clinic (Chapter 7). These analysis chapters detail and explore the data generated, drawing out key findings and interwoven themes from children and parents' accounts. The findings are presented independently in these chapters, rather than in relation to the wider literature ensuring the quality and nuance of the stories provided were captured and uninterrupted by comparison to other such empirical studies and theoretical perspectives.

Chapter 8 discusses the key findings of the study alongside reviewed literature, empirical studies and explores the wider theoretical contributions of the study. To conclude, it will summarise the thesis findings, limitations and possibilities for future research and insights for clinical practice. There are four key appendices at the end of thesis including: recruitment documentation, interview and observation schedules, copies of the additional research tools used, and the two published articles I have co-authored during my doctoral studies (Harden et al, 2016; Black et al, 2017).

Chapter Two: Literature Review

1. Introduction

Chapter 1 outlined the context of this research, highlighting the lack of sociologically-framed research on childhood epilepsy directly addressing children's own experiences of the condition and its treatment and management. Research has shown that children experience epilepsy differently to their parents and are capable of expressing their views and accounts (Ronen et al, 2001). Attaining their perspectives of childhood epilepsy provides unique and valuable insight into their experiences as well as an avenue in which to scrutinise the concept of children's agency and its connections to children's involvement. How children are conceptualised by their parents, and within research, will however, influence how they are involved in such care and represented in research. Similarly, how care is constructed alongside children (and childhood) is also instrumental with regards to the opportunities for children to be agentically involved in their treatment and management regimes.

Firstly, literature from the sociology of childhood will be drawn on to explore how children and childhood are constructed, alongside the concept of agency and the how both are influenced in the context of illness. A detailed exploration of care will then be undertaken, examining the theoretical and practical conceptualisations of care in the context of the family and childhood chronic illness. In particular, how care has been constructed by feminist and disability writers will be explored, alongside an ethic of care and the concept of interdependency. Following this, care in clinical contexts, such as routine epilepsy clinic appointments, will be examined. Key sociology of chronic illness concepts (namely, biography, normalisation and stigma) will then be examined to explore how chronic illness becomes embedded by individuals in to their lives to further understand children's and parents' experiences of childhood epilepsy. Finally, a summary of the main points will then be presented, alongside the research aims and questions developed.

2. Sociology of Childhood

Accounts of health and illness have been considered from a range of perspectives and positions in the social and health sciences over the years. Much of the research

concerning children's health and illness, just as with childhood epilepsy research, has overlooked children's own perspective (Sartain et al, 2000; Brady et al, 2015). Rather, as explored in Chapter 1, focus has primarily centred on parental narratives of chronic conditions, parents' views on their child's capacity, and parents' own understandings of their child's condition and coping styles (Olin Lauritzen, 2004; Koller et al, 2015). Alongside the legislative and policy changes outlined in chapter 1, the interest in obtaining children's accounts and experiences of illness has been further encouraged by developments in the sociology of childhood (Moran-Ellis, 2010; Tisdall and Punch, 2012).

In 1973 Charlotte Hardman asked: 'can there be an anthropology of children?' (Hardman, 1973/2001). Hardman proposed that children should be studied in their own right, and not as passive objects in society, establishing interest in the study of children and childhood. Among others, Hardman, argued that interest in children had primarily been concentrated within the fields of developmental psychology and education, guided by models of child development and socialisation (James et al, 1998). Adults were seen as mature, rational and competent, whereas children were viewed as 'less than fully human, unfinished, or incomplete' (James et al, 1998). Qvortrup (1994) emphasised this through suggesting children were constructed as 'human becomings' rather than 'human beings'. Consequently, children were primarily seen in terms of their future worth: what they could or would 'become' as adults (Saporiti, 1994: pp.193). Childhood was conceptualised, in this regard, as an incompetent, passive, and dependent stage of the life course (Purdy, 1992; Hockey and James, 1993; Philips, 1997), affording children little autonomy or control outside their future potential (James et al, 1998; Valentine, 2011).

There is, however, an inherent issue in polarising children and adults as 'becomings' or 'beings' and for implicating concepts of competency and agency in similar dichotomous manners. It is argued that everyone, including adults, could be considered 'becoming' (Lee, 2005). Everyone can be considered as developing and changing as they experience different social contexts and are exposed to new situations over their life course (Lee, 2005; Prout, 2005; Uprichard, 2008). Adulthood and childhood are not static concepts immune to change over time and influenced by those around them. Hence, both adults and children are constantly in a state of becoming (Kesby et al, 2006).

Given this critique, sociologists of childhood have moved away from such unitary and dichotomous notion of adulthood and childhood. Instead, James and Prout explicitly called for the study and theorisation of children as social actors, emphasising the concept of agency, and seeing children as members of society in the here and now (James et al, 1998; Moran-Ellis, 2010). Within this, childhood is instead theorised as a social construction, variable among different socio-cultural contexts (Mayall, 2002). Children are viewed, in this regard, as competent, active actors (someone who participates in social life) capable of reporting on and, to an extent, shaping their own lives (Mayall, 2002). They are active agents (participation is negotiated and has a social effect) and co-constructors of their social world (Mayall, 2002; Moran-Ellis, 2010; Tisdall and Punch, 2012).

Furthermore, focus has shifted to recognising the diversity of children and childhoods (Singal and Muthukrishna, 2014). Children are subject to different structures and discourses; they are different ages, genders, ethnicity, and from diverse socio-economic circumstances, with various capacities and capabilities (Prout, 2005). These structures are influential on children's experiences of health and well-being, with implications for how children are able to be agentic in dealing with their health (Brady et al, 2015). For children with epilepsy wider societal attitudinal concepts of epilepsy and the stigmatisation of the condition can be further influential.

In previous homogenised conceptualisations, childhood has widely been presumed to be a healthy state. James and colleagues (1998) have suggested that childhood illness represents a 'condensed symbol of childhood' (pp.97). Childhood illness is accordingly seen as a threat to 'normal' childhood and can be seen to perpetuate certain conceptualisations of children, intensifying concepts of dependency and vulnerability (Prout et al, 1999; Young et al, 2002). This is exemplified by Hightower and colleagues' (2002) who concluded after carrying out a descriptive study of the lived experience of children with epilepsy: "Children with epilepsy seem to struggle more than children with other types of chronic illness to achieve what society may perceive as a 'healthy childhood'" (pp.134). The comparison to a 'healthy childhood' illustrates how children are conceptualised as 'natural innocents' (Mayall, 2002) who should be sheltered from the burden of the illness in order to protect their futurity (Young et al, 2002). This invariably reflects 'unhealthy/ill childhoods' as disruptive, as well as suggesting that a 'healthy childhood' should be aspired to, even when a

diagnosis of epilepsy has been made (Alderson et al, 2006). Maintaining this view of children and childhood in the context of illness can present challenges to agency and autonomy.

2.1 Conceptualising children's agency

Agency has become ubiquitous in discussions of sociology of childhood, and subsequently valuable concept for this study to examine (Ahearn, 2001; Valentine, 2011). However, there has been minimal reflection on what agency means, often resulting in it being referred to in an indeterminate sense (Oswell, 2013; Moran-Ellis, 2013). Definitions of agency that have been put forward have been critiqued as too simplistic, too narrow or too opaque; more commonly it has simply been referred to as a synonym for 'to act' (Ahearn, 2001; Valentine, 2011; Moran-Ellis, 2013). This, in part, is due to the eagerness of the sociology of childhood discipline to recognise children as social actors (James et al, 1998) or, as Mayall (2002) described, as social agents — that is, people who make things happen (as explored above). Through reflecting on the many attempts to conceptualise agency, Ahearn proposed an encompassed definition: "agency refers to the socioculturally mediated capacity to act" (pp:112), drawing out the distinctions between 'to act' and being agentic. Agency is thus broadly understood as the capacity 'to do' through intention (Ahearn, 2001; Ritzer, 2005).

However, beyond this definition (action with intent) there has been little critical examination of what agency or being agentic means (Valentine, 2011; Ahearn, 2001). A number of sociologists of childhood have begun to question what is within the 'black box' of agency (Campbell, 2009; Oswell, 2013; Moran-Ellis, 2013), asking where is agency located? What does it mean for an act to be agentic? Do all children, irrespective of age, have agency? What does it mean to have the capacity to be agentic? Through exploring such questions and unpicking the assumptions around the concept of agency, a more nuanced conceptualisation can emerge.

If, taking the proposed definitions from above, agency is to be understood as 'to act with intent', then it is inferred that the agent (person acting) must be able to communicate the reasons or the intention of their actions (Ahearn, 2001; Ritzer, 2005; James, 2009). However, being able to communicate presumes cognitive, linguistic and

reflexive skills, which can exclude children and others without such developed communicative skills (Shakespeare, 2001; Watson, 2012; Moran-Ellis, 2013). Following this, if agency involves purposive action then any action must be discernible as having a purpose, and if it also involves making some change in a situation, that change needs to be both observable and reliably linked to the action (Moran-Ellis, 2013). Again, this can exclude children who can have a limited scope for making noticeable changes to a situation (Moran-Ellis, 2013). As a result, agency could be argued to be unachievable and inaccessible for children, reflecting arguments explored previously of children as 'becomings' and not yet fully capable (Lee, 2005).

However, there is a wealth of empirical literature documenting and analysing children's actions and interactions, generating analysis which support classifying children as individuals who have the capacity to be agentic and are demonstrably exercising such agentic activity in their everyday worlds at even quite young ages (Lam and Pollard, 2006; Olli et al, 2012; Moran-Ellis, 2013). This extends to numerous studies documenting children's agentic contributions in healthcare and chronic illness contexts (e.g. Garth and Aroni, 2003; Bluebond-Langer and Korbin, 2007). The documented agency and agentic behaviour has been wide ranging, from being able to clearly consent to surgery to more subtle and discernible agentic actions such as avoiding certain activities (Alderson et al, 2006; Brady et al, 2015). Through discussing agency and engagement in the early years Moran-Ellis (2013) emphasised subtle agentic actions of young children, illustrating that children can manage their agentic actions without necessarily disturbing or challenging formal social order. Rather, young children mobilised material resources to stimulate a required action, without necessarily performing it (Moran-Ellis, 2013).

Accordingly, and in considering the accumulation of agency, there can be no specific point at which being agentic can be claimed, in either childhood or adulthood. Children cannot be assumed to be agentic at a given age or by simply 'doing' a particular degree of action (Mayall, 1998). There is no predetermined stage to which all children progress from a non-agentic 'becoming' to an agentic 'being' drawing on previous arguments of everyone developing throughout their life course (Lee, 2005). Similarly, there has been much discussion of agency in polarising, binary terms – something that children have present or absent (Valentine, 2011; Oswell, 2013). As Oswell argues, agency should not be "a simple binary, having or not having agency"

(2013; pp.269). Such an understanding of agency has been attributed to an overreaction to prior conceptualisations of children as passive and dependent i.e. without agency, non-actors (Holt, 2011). Thus, agency cannot be considered as an innate characteristic that emerges as children age. Rather it can be constructed as an accomplishment of situation, shifting attention to interactional, contextual dimensions rather than internal, individual characteristic (Zimmerman, 1987; Papadimitriou, 2008)

Consequently, the scale and scope of a child's capacity to be agentic is inevitably dependent on the context (Moran-Ellis, 2013). Willmott (1999) argued that the capacity to be agentic depends on the power individuals can mobilise to implement their desired goal or achieve their intention. Children's generational position in society, their multiple social positions within inter- and intra-generational relationships "all offer different opportunities and constraints to act and, in doing so, exercise their agency" (James, 2009: pp.43; Mayall and Zeiher, 2003). Children's agency can hence be mediated by generational power imbalances and connected societal conceptualisations of childhood (and parenthood). Through these societal conceptualisations, children's agentic actions could be overlooked, misattributed or misconstrued.

Adult conceptualisations of children's agency can promote an almost universal acceptance of agency as a positive (Valentine, 2011). Children's actions or behaviours are only deemed to be agentic if positive or socially desirable: if children behave in an appropriate manner. Otherwise, the child is deemed to be acting inappropriately, misbehaving or making incorrect decisions – not necessarily illustrating agentic behaviour (Mayall and Zeiher, 2003). Both forms of behaviour or actions, are agentic, but can be conceptualised differently by adults. Through this conceptualisation there is the risk of privileging children with *more acceptable* applications of agency that those who do not display such agentic action (through rationality and choice) in conventional ways (Valentine, 2011). Yet, children should be able to assert agency in different, perhaps socially 'wrong' ways (Hanson, 2016).

How others conceptualise agency and the structural, contextual circumstances (or 'arenas of action') can serve to shape children (and adults) opportunities to exercise and display agency and consequentially be viewed as competent social agents

(Hutchby and Moran-Ellis, 1998). The capacity to be agentic is consequently a product of the interplay between individual desires and the exercise of power and authority by other actors in given situations. Accounting for this influence, further illustrates that agency is not an internal property of the self. Agency is rather an interactional concept – not a property possessed by the individual. When children act in strategic ways as actors and agents their actions reflect, maintain or create, social orderings; they are being socially competent even if they are not able to change the situation they are in (Moran-Ellis, 2013). Hence, children's agentic potential can be understood as an interactional accomplishment, that is mediated by the socio-cultural and personal resources available and the interactive dynamic of those involved in different situations (Moran-Ellis, 2013; Wyness, 2015).

Therefore, agency can be understood as a complex process that is dynamic, multidimensional, and shaped through context and others interactions, and is not always enacted by all children, at all times. This emphasises the importance of situating children's agency and competence within situations children act (Hutchby and Moran-Ellis, 1998; Wyness, 2015). As well as recognising and exploring the material and socio-cultural resources they have available and are required to draw on in order to agentially operate and how others, notably adults can implicitly or explicitly influence their enactment (Moran-Ellis, 2013). Thus, further recognising agency as contextual and contingent (Moran-Ellis, 2013).

In attempting to acknowledge the complexity of agency and drawing attention to the accumulation of agency, its distribution, and interactional and contextual influencers, Robson and colleagues (2007) suggest a continuum could be more useful than a binary approach of agency. Robson and colleagues (2007) posit that a child's agency could fall along the continuum depending on the (un)constrained context, created and expected identities (their own and others conceptualisations), their positions of power(lessness), life-course stage, and state of emotions and well-being (Robson et al, 2007; Punch, 2016). Klocker (2007) has taken this continuum further with the notion of thickening and thinning agency to explore how children's agency can be (un)constrained in different contexts emphasising its interactional nature. Additionally, Bordonaro and Payne (2012) have introduced the concept of 'ambiguous agency' for when children's agency threatens or goes against the existing moral and social order in society and iconic conceptualisations of childhood.

Thus, children's agency must be a contested and scrutinised concept rather than taken-for-granted or assumed inherently positive, desired or available to all. This is of particular salience in the circumstance of childhood chronic illness, where there is often a range of factors, situations and contexts where children may not wish to utilise or even be deemed capable of expressing agency. Consequentially, children's agency can be seen as both a starting point to children's autonomy and means to achieving certain ends (e.g. children's interest being authentically articulated and engaged with) as well as an end in itself (an embodied sense of agency) (Prout, 2000; Wyness, 2015).

2.2 Children's agency in the context of illness

In the context of illness children and agency can become exposed to a host of further situational and institutional influencers. In healthcare contexts chronological age and (perceived) maturity are often used as benchmarks for involvement and capacity for agency, illustrating a concrete 'line in the sand' between vulnerable and competent. This is further reinforced through various legal rulings including Gillick competence (Brook, 2000; Gabe et al, 2004). The focus on children's competence in healthcare raises an important question: what happens to vulnerability with such heavy focus on agency (Bluebond-Langner and Korbin, 2007; Philo, 2011)? There is an intrinsic tension between recognising children's agentic potential versus acknowledging their position of vulnerability in certain contexts (Borbonaro and Payne, 2012). This is especially apparent in the contexts of chronic illness and patient involvement. With patient-centred care now a core element of British medical discourses, patient involvement is central (Armstrong, 2011). Yet, with much of the research regarding patient involvement focussed on adults, there has been limited attention paid to children's involvement, and their ability to be agentic, in such contexts and the resultant intersection of vulnerability/autonomy.

As illustrated previously, opportunities for children to enact agency and to be involved, form partnerships, and are shaped by the preconceived notions of childhood and different conceptualisations of their competence and vulnerability held by those around them (Gabe et al, 2004). It could be easily assumed that children are relatively passive and conforming when faced with illness – lacking in agentic capabilities (Mayall, 1998). This assumption would be inaccurate, however, as children do exercise agency in healthcare decisions and contexts. It has been illustrated through numerous

studies that children demonstrate an active and agentic role in the management of health risks, their conditions, and interactions with healthcare services (e.g. Tates and Meeuwesen, 2001; Bluebond-Langner et al, 2010; Mayall, 2015). In such studies, children developed a repertoire of strategies to cope and sometimes to resist adult defined agendas to their healthcare (Bluebond-Langer and Korbin, 2007; Brady, 2014; Mayall, 2015). Yet, adults, including parents and healthcare professionals, remained unaware of the ways in which children were interpreting information on health and making it meaningful to their lives (Alderson et al, 2006; Brady et al, 2015). Consequentially, children draw and enact agency, through their own understandings and meanings of their illness and healthcare associated with it.

This is exceptionally acute when children actively 'take' responsibility (illustrating agentic actions) for their health and medication and when their ideas of acting responsibility differ from that of their parents. As LeFrancois (2007) states, when such views differ, parents are likely to elicit a protectionist response, suggesting that they may deem these children and young people as both vulnerable ('too young') and incompetent ('immature'), by virtue of their status as a child with a chronic illness (Brady 2014). This highlights how a child's perceived vulnerability and lack of agentic potential (in such situations) is influenced by others' judgements on the 'correctness' of their involvement. Similar arguments are used when evaluating children's knowledge and expertise of their chronic illness (LeFrancois, 2007).

In previous discussions of patient knowledge having experiential based knowledge and insights of a condition, have been referred as an expert of the condition (Busby et al, 1997; Monaghan, 1999; Prior, 2003). Patients' own experiences have frequently been described as being able to provide deeper insights into their condition, accessing a direct experience that alludes healthcare professionals who may have studied the condition in great depth, affording them as patient experts (Prior, 2003, L'Espérancea and Orsin, 2016). The valuation and recognition of such 'insider' experience is varied (Thorne et al, 2000), especially in the context of childhood chronic illness (Mayall, 1998; Coyne, 2006a; Brady et al, 2015). Research has shown that even chronologically young children are competent reporters of their illness experiences (Alderson, 1993) and that children can understand complex information if presented appropriately (Alderson et al, 2006). Similarly, children with disability are not viewed as necessarily having problems or being problems, but as having differing capabilities

and means of illustrating agentic action (Tisdall, 2012; Curran and Runswick-Cole, 2014).

As noted earlier, how children approach health and illness has to be understood relationally: being healthy or ill, competent or not, takes place in relation to others including parents (Brady et al, 2015). Bringing parents' experiences of children's agency in to the discussion offers a nuanced understanding of how children's own experiences can be moulded and influenced by their parents (Alanen, 2001; Mayall, 2002). While not losing sight of parents as agents, it is particularly important to account for the relations of power and control within which parent-healthcare professional encounters and constructions of children and childhood are embedded (Wilhelmsen and Nilsen, 2015). This is demonstrated through the body of literature that explores how parents' and families seek to normalise a childhood chronic illness, bringing it into part of the family narrative (see: e.g. Prout et al, 1999; Morse et al, 2000; Stewart, 2003; Emiliani et al, 2011); a concept that will be explored in more depth in the upcoming section. Consequentially, although children are social autonomous actors in their own lives, the role of parents in chronic illness care cannot be ignored. A number of studies have shown that while children have their own perspectives and concerns, parents remain primarily responsible for accessing care for their child and establish home-based treatment and management regimes (Beacham et al, 2013; Trnka, 2014). This emphasises children's dependency on parents irrespective of their own autonomy.

This discussion of agency in the context of illness also serves to highlight the distinctions between involvement, participation and agency. These terms are often conflated and used synonymously, particularly in regard to children's participation in their healthcare. Participation has been widely used to describe the ongoing process of information sharing and engagement between children and adults regarding situations that influence children's lives (Tisdall, 2017). Involvement emerges as a result of active, and valued, participation - a shared dialogue between children and adults built on mutual respect, providing children genuine influence on the matters that shape their lives (Tisdall, 2017; Percy-Smith and Thomas, 2010).

Children's healthcare policies frequently emphasise participation and involvement in healthcare decisions advocating it as a positive, and there are many such examples of

children and young people being given a choice and the opportunity to express their thoughts and feelings in these settings (Vis et al, 2010). However, there is less evidence as to whether such choices or resultant decisions, or opportunities for involvement or participation were acted upon or resulted in more responsive services or allowed children to demonstrate agentic contributions in such circumstances (Vis et al, 2010; Coad and Shaw, 2008). Drawing on Klocker's (2007) metaphor, healthcare settings can be seen to 'thinning' children's opportunity to be agentic. Furthermore, without providing appropriate tools, space or opportunity for children to be agentic actors their participation and involvement within their healthcare can become meaningless and tokenistic (Hart, 1992). It is thus vital to reflect on the nature of children's involvement and participation to understand whether it truly presents an invitation to be agentic through presenting a 'thickening' circumstance (Klocker, 2007).

Children's involvement and decision to exercise agency is therefore formed within the boundaries set by how their agentic actions are viewed and their position in relation to adults and wider societal views of what childhood should represent (Jackson and Scott, 2000; Foley et al, 2001). Yet, accessing children's accounts challenges and sheds light on the ways that they exercise agency to make decisions and participate in their healthcare (Brady, 2005). The next section of the literature review will explore the broad topic of care by examining the theoretical underpinnings (of family, feminism and disability studies), and its application to childhood epilepsy care in the home and in a clinical setting.

3. Care: Conceptualisation and Concepts

Care is a central human practice that shapes everyday lives and relationships (Noddings, 2002). Examining the nature of care and caring is a growing area of investigation, particularly regarding chronic illness where care takes on a further array of complex meanings and functions (Nettleton, 2013). This is particularly the case in the context of childhood epilepsy, where multiple care needs can involve the whole family and a wide range of healthcare professionals. However, 'care' and 'family' are neither discrete nor simple constructs: both are multifaceted concepts that intersect and overlap with one and other while incorporating issues of power, autonomy and

responsibility (Brannen et al, 2000; Morgan, 2011). Additionally, as constructions of care intersect with understandings of family, both are further subjected to re-construction by individuals and wider society (Brooker, 2010). During processes of construction and re-construction these concepts can become loaded with inherent assumptions that influence exactly how they are conceptualised (Morgan, 2011).

Care is consequently context-specific (Brannen et al, 2000). The context within which individuals are involved in caring activities frames and influences what is seen as care, how it is performed and received, and how different roles and identities in this regard are shaped and formed (McLaughlin, 2006). These complexities can also be replicated and further complicated in a hospital or clinical context where care and caring activities take place in a formal healthcare setting (Gabe et al, 2004; Curtis-Tyler, 2012). Given these complexities, the nature and conceptualisation of care will be examined to allow for a detailed examination of the nature of care, caring practices, and caring relationships to be explored in-depth in a family and clinical context. This section will build on this emerging interest by considering care experiences and involvement in the context of childhood epilepsy. Furthering the wider discussion of chronic illness care away from 'burdensome' and on those providing care, towards an exploration of children's agentic involvement and experience (Brannen and Moss, 2003; Brooker, 2010; Bath, 2013).

The section of the literature review will firstly draw upon relevant theoretical understandings of family, drawing on recent arguments advanced by sociologists of childhood regarding children in the family context. Key conceptualisations of care and how it has previously been discussed by feminist writers and disability studies writers will then be critically explored for applicability in examining childhood epilepsy care experiences and involvement. Then, concepts of care that have emerged from these perspectives will be discussed with reference to childhood chronic illness before a summary is produced. The understanding produced will move beyond simple descriptions of circumstance and assigned responsibilities to examine the roles and responsibilities that parents' and children assume in the context of childhood epilepsy, at home and in the clinic.

3.1 Family and Care

In the context of childhood epilepsy and (most) chronic illnesses, the majority of health-related care takes place in the home by those experiencing illness and by their families. For children with epilepsy, care is multidimensional incorporating treatment regimens and management regimes, as for the most part, there is no known cure. From the point of an epilepsy diagnosis parents, usually mothers, take responsibility for implementing and enforcing treatment and management regimens for their child, altering the child-parent caring relationship (Fine, 2005; Venter, 2011). Caring practices within this context also shift; children and parents become involved in the child's need to take anti-epileptic medications and adapt to seizure management and safety protocols (Appleton and Marson, 2009). These treatment and management regimes are incorporated into family care routines. Thus, the context within which care is enacted - i.e. the family - influences how care is experienced and understood by those involved.

Family and family life are common, almost self-evident concepts that many sociologists and wider academics are familiar with (Morgan, 2011). For much of the twentieth century, 'family' has been conceptualised as the 'nuclear family': two adults, (the parents: a mother and a father) and their (biological) children (Williams, 2001; Wyness, 2014). This conceptualisation has been the basis of numerous policies and health and social care initiatives (Morgan, 2011). The strong institutional underpinning of this conceptualisation of family exerts considerable moral force, creating a positively endorsed image of what family is and does (Dermott and Seymour, 2011; Morgan, 2011).

Within this traditional conceptualisation of family, 'care' is seen as the engine of family life and caring responsibilities as its intrinsic obligations (Brannen et al, 2000; Fine, 2005). The complex relationship between caring responsibilities and family obligation to provide care constructs a taken-for-granted expectation of household members. Parents, especially mothers, are charged with caring for and appropriately raising their children to become suitable model adults for society (Mayall, 2002; Murray and Barnes, 2010; Wyness, 2013). This embeds powerful socio-cultural stereotypes regarding parents' responsibility to protect and care for their children (Wyness, 2013). Furthermore, this conceptualisation compounds stereotypes about and contemporary concerns regarding children, including notions of dependency, vulnerability, and futurity (Mayall, 2002; Murray and Barnes, 2010). These socio-cultural stereotypes have

masked children's agency and autonomy and have burdened parents with vital, hidden, caring responsibilities (James and Curtis, 2010; Wyness, 2013). Children are seen as a product of their parents, with care being passively received and concealed under the broader notions of family and support, as illustrated through the previous section, and has consequences for opportunities of childhood agency and involvement (Fine, 2005; Murray and Barnes, 2010).

These presumptions and stereotypes surrounding 'family' as a term and a concept have framed how childhood epilepsy has been explored to date. Previous research has used the traditional conceptualisation of family to explore the 'burden' of childhood epilepsy for children and parents on their quality of life and their approach to coping with the altered caring practices required (Admi and Shaham, 2008; Moffat et al, 2009). While useful, this approach has offered minimal scope for examining children's own experiences of care, as illustrated in chapter 1. The insight attained is only partial and does not capture the whole family's experiences of care (both giving and receiving), the caring relationships, or children's potential contributions to their own care.

In seeking to capture the changeable nature of family life and the different relationships that family can involve, British sociologist David Morgan (2011) has asserted the need to focus on and emphasise the significance of 'family practices'. These are the dynamic processes through which 'families' are created every day. Morgan (2011) roots the family in everyday life and routine events and processes, where he argues that individuals conceptualise actions and activities as family practices. These practices are continuously constructed processes in which family members transmit emotions, engage in caring activities, and spend time together actively constituting and reconstituting their sense of family (Morgan, 2011). This influential idea of family practices - or the 'doing of family' - provides a useful frame to explore the complex realities of family life, particularly in the context of childhood chronic illness care (Chambers, 2012). Care is still very much intertwined, with caring responsibilities and obligations being more explicitly represented as something that is 'done' within and by family (the 'doing of family') (Morgan, 2011).

Janet Finch has further added to this by explicitly linking family practices with the concept of, 'displaying family' (Finch, 2007). Finch (2007) offers the notion of

'displaying' families to explore various components of family. 'Displaying family' provides a way to understand the ever-changing concern of 'what the family is', how the family might be understood by individuals in it, and how family is communicated by individuals to themselves and others (Finch, 2007; Almack, 2008; Davies, 2011; Dermott and Seymour, 2011). Morgan and Finch's notions can assist in exploring everyday care and family in broad terms, privileging individuals' own definitions and constructions of caring and family practices (Davies, 2011). How children and parents' independently and together choose to 'display' their caring practices provides a lens to explore a more nuanced examination of everyday life in the context of childhood epilepsy and its associated treatment and management. Thus, for this study, 'family' can be understood through contributions of children and parents and how they choose to display their care and caring practices. Accordingly, it is important to capture both children and parents' accounts of involvement in care.

The conceptualisation of family as a concept within the sociological literature has been critically examined, moving from a traditional stoic structure of society to a more sophisticated, fluid understanding of complex interconnected webs of relationships and practices (Morgan, 2011). With this shift, our ability to explore family and 'what it does' in various contexts, including that of chronic illness, has moved towards a more nuanced detail (Finch, 2007; McLaughlin and Clavering, 2012). Thus, moving beyond simple descriptors of family life and allows for a more rigorous exploration of care, caring practices, and the caring relationship and the negotiations of them which emerge in the context of childhood epilepsy.

3.2 Conceptualisations of Care

As traditional views of family have been contested, so too have the assumptions of care and its deep-rooted position within the family. Feminist sociologists were the first to consider care at a conceptual level, arguing that care was a form of (oppressed) labour hidden in the bounds of family and home (Williams, 2001; Oakely, 1974). For these writers, women were seen as victims of the assumed gender-based roles of care, with limited recognition of the 'caring' work that they carried out as the societally-regarded 'natural' carers of the family (Noddings, 2002). This highly gendered foundation of care, strongly linked to the constructions of motherhood and 'natural' maternal sentiments, created a moral obligation for women to provide care both in

terms of motherhood and more generally (Dalley, 1988). Feminist sociologists sought to liberate women from this obligation and to instead promote their self-sufficiency and independence (Sevenhuijsen, 1998; Phillips, 2007).

While path-breaking at the time, and important for both feminist activism and ultimately policy change, such views of care neglect the emotional aspects and bonds that are caught up in care as a concept. Caring involves emotional exertion, drawing on familial relationships and ties and resulting in family and care being intertwined to form a sense of duty (Kleinman, 2012). In seeking to address the emotional and familial ties to care, Noddings (2002) and Ungerson (1983), suggested that caring could be conceptualised in two distinct ways: as *caring about* and *caring for*. *Caring about* referred to the feeling part of caring, with a thought toward the dependent or the one in need of care; *caring for*, on the other hand, reflected the practical work of tending for and caring for others (Noddings, 2002). Noddings (2002) connected this distinction between types of care and gender differences. Men were understood to be more likely to *care about* dependent children and others at home, but it was women who were assigned the duties of care work and its associated emotional labour and bore the burden of *caring for* as a result (Ungerson, 1983; Noddings, 2002). This balance of gendered caring roles has however been readdressed as father's roles in care have been further explored (e.g. McNeill, 2004; 2007; McNeill et al, 2014). Care, in this regard, is constructed as either an emotional moral ethic or as physical labour, built on familial relations with the home as its 'site'.

The approach of conceptualising care in terms of *caring for* and *caring about* has been heavily critiqued. In particular, the failure to acknowledge the relational element of care, in as much as care involves not only the care-provider but also the care-receiver (Williams, 2001). Both participants in care are locked into an inter-personal dynamic in which the care-provider holds more 'power', consequently influencing their relationship and the manner in which such care can be perceived (Williams, 2001; Alanen, 2001). Furthermore, this approach to care assumes that the site of care is the heterosexual 'normal' family, with mothering seen as the main point of research attention (Barnes, 2011). This replicates previous discussions on the critique of what is meant by 'normal' family. Moreover, there was little recognition of consecutive and sequential periods of care and the associated impacts that this could have on care-providers and wider family life (McLaughlin, 2006).

Much of the critique to this approach of conceptualising care has come from disability studies writers who argue, that on a fundamental level, the notion of care is inappropriate and disempowering (Watson et al, 2004). Above all, disability scholars have opposed the unidirectional perspective of care from the position of the carer. This position frames discussions of care as burdensome and as a moral familial obligation (Morris, 1993; Kittay, 2011). Conceptualising care in this manner, according to disability studies writers', embodies an oppressive stance in which the practices of carers (both paid and unpaid) uphold those in need of care in a position of dependency (Kroger, 2009). Richard Wood, a disability studies scholar, goes as far as stating that "[d]isabled people have never wanted or asked for care" (Wood, 1991: pp.199).

For disability studies scholars, dependency or the notion of being 'dependent' on another's care-giving is often considered confining and patronising (Watson et al, 2004). Moreover, under this terminology those requiring care are considered passive within the caring relationship. They are viewed as 'burdens' and 'takers' (Shakespeare, 2000; Fine and Glendinning, 2005). This can result in a position whereby those who are said to be in need of care are assumed to be unable to exert choice and control – two key aspects of empowerment and autonomy – over the care that they receive (Kroger, 2009; Williams, 2001). Disability studies scholars have accordingly promoted the need for individualism and autonomy in care (Watson et al, 2004; Kittay, 2011). In this regard, they have sought to move away from a construction, and practice, of care that is in itself disabling and preferential to the care-provider (Morris, 1993; Watson et al, 2004).

Accordingly, disability studies writers have sought to avoid both a disabling language of care and the analysis of those who 'care for' (McLaughlin, 2006). Given this, disability studies scholars have sought to promote alternative concepts and terminology around the notion of 'care' instead. Tom Shakespeare, a leading UK disability studies scholar, advanced the idea of 'help' to refer to the reciprocal relationship where help is afforded on a mutual basis. As he put: "In the performance of help, we take on different and changing roles" (Shakespeare, 2000: pp.85). Alternatively, the terms 'support' (Finkelstein, 1998) or 'assistance' (Kroger, 2009) have been used when speaking about the needs of disabled people (Williams, 2001). These different conceptualisations of care have sought to transfer care from an emotional

concept, centralised around unequal relationships, to a less personal and more contractual relationship (Watson et al, 2004). This transformation of care and the caring relationship, according to the disability writers', addresses power imbalances between the carer and the cared for. Theoretically it provides the person in need of care greater control and choice over their life (Morris, 2001) and offers the opportunity to include the notions of autonomy and independence in the conceptualisation of care (McLaughlin, 2006). Nevertheless, there has been a reticence within disability studies to explore care (or help, support, or assistance) in the lives of those who care for disabled people, including in the context of family or childhood chronic illness (Kittay, 2011; McLaughlin and Clavering, 2012).

Disability studies writers have provided different perspectives on care by highlighting those whose experiences of care were marginalised in previous constructions of the term by feminists and wider care-based policies. The discussion created by disability studies writers has pointed to the need for care constructions to take into account how care can be shaped, including: power differentials in care relations, the implications of independence and dependence, the many sites of care, and the different requirements of care. Many of these influences connect with dimensions apparent in child-parent relationship in the context of chronic illness care; this will be discussed further in section 4.1. Yet, the stance adopted by some disability writers has been criticised as too simplistic, offering only a radical rhetoric to policy and politics (Shakespeare, 2006; Watson, 2012). The insufficient recognition of impairments within this stance also disregards those children and adults who have impairments that are limiting (Thomas, 1999).

However, a conceptualisation of care based on either feminist or disability studies underpinnings alone may not be suitable for examining care in the context of children and childhood epilepsy (Brannen and Heptinstall, 2003). An approach that considers all involved in care and the caring relationship, irrespective of age or perceived dependency, is required. An alternative conceptualisation of care put forward is the notion of an 'ethic of care'. This approach attempts to address the concerns of gendered responsibilities and assumptions while recognising the care involvements of all individuals (McLaughlin, 2006). Care ethics was first developed by psychologist Carol Gilligan to explain the differing aspects of moral reasoning and development of men and women. Gilligan describes an ethic of care as an ethic grounded in voice and

relationships, emphasising the importance of everyone having a voice (though dependent on gender), being listened to carefully and heard with respect (Gilligan, 1982). The ethic of care, accordingly, highlights the relatedness and responsiveness of care and caring practices (Gilligan, 1982).

Joan Tronto (1993) took the ethic of care beyond its gendered starting point to develop a moral and political concept through which care could be further explored. Tronto argued that previous iterations of an ethic of care were fragmented, obscuring any attempts to explore autonomy and dependence surrounding care (Tronto, 1993). The concealing of autonomy in care can perpetrate structures of power, resulting in an 'otherness' being created within the caring relationship, i.e. care-recipient vs. care-provider (Tronto, 1993). Tronto asserts that an ethic of care must acknowledge potential power relations, inclusion, citizenship, and interdependency, all of which could shape how care is understood and experienced (Tronto, 1993; Rummery and Fine, 2012).

Incorporating these ideas and further expanding her proposed conceptualisation of an ethic of care, Tronto put forward four dimensions of care. The first of these is *attentiveness*, a caring about dimension that is underpinned by noticing the needs of others (Tronto, 1993; pp.127-134). The second is *responsibility*, the taking care of and the assuming responsibility of care. For Tronto, responsibility does not have the same connotation as obligation as was previously seen in constructions of care (Tronto, 1993). *Competence* follows, highlighting the activity and practicalities of care involved in care-giving and the insurance that it is of an adequate quality. Finally, *responsiveness* reflects the care-receiving dimension of care: the responsiveness to receive care. Responsiveness also emphasises awareness to one's own vulnerabilities and the appreciation of the different positions and negotiations of the care-giver and care-receiver, whilst also suggesting the need to keep a balance between the needs of both (Tronto, 1993). It is through the integration of these four dimensions of care that Tronto posits that an ethic of care is produced, recognising the variation across differing caring roles, contexts and situations. These dimensions echo previous distinctions between caring for and caring about but go further to explore the interconnectedness and autonomy of care (Rummery and Fine, 2012).

In constructing an ethic of care, Tronto (1993) rejects the dominant notions of individualism and autonomy. Instead, care is seen as dynamic, occurring as a partnership between the care-receiver and care-provider to create a caring relationship. Tronto (1993) emphasises that care, vulnerability and mutual dependence are all central concerns of life and shared by all – they are not only descriptors of certain groups of people, e.g. children, older adults or individuals living with disabilities (Sevenhuijsen, 1998; Kroger, 2009). An ethic of care emphasises the notion of shared vulnerability and a dynamic caring relationship creating interdependency (Tronto, 1993). The ethic of care consequentially offers a constructive approach to explore childhood epilepsy; it emphasises the varying responsibilities and relationships, the contexts of caring, and allows for the examination of children’s involvement, whilst still respecting the care work and value provided by parents (Cockburn, 2005; Hamilton and Cass, 2017).

As a concept, interdependency provides the opportunity to further develop our understanding of care and caring relationships. Interdependency can be defined as a mutual, variable view of dependency amongst individuals, demonstrating a mutual dependency that can fluctuate over time (Watson et al, 2004). It is primarily concerned with principles of equality, empowerment, choice, and control (Kroger, 2009; Veron and Quereshi, 2000). In a caring context, interdependency can be contrasted with the notion of dependency and a dependent relationship (Watson et al, 2004). Interdependence can instead be used to draw attention to the potential power differential that can emerge in the caring relationship whilst also acknowledging that there is a shared vulnerability (and dependency) for care needs (Kittay, 2011).

The move towards recognising interdependency as an alternative to dependency has been welcomed by many disability studies scholars (Watson et al, 2004). Interdependency puts greater emphasis on choice, as well as actively engaging all involved in the caring relationship (Fine and Glendinning, 2005). As Williams states: “[w]e are all, after all ... the givers and receivers of care to and from others” (2001: pp.486-7), irrespective of age or perceived life stage (Moullin, 2007; Mayall, 2015).

There has, however, been criticism of the term interdependency. Kittay (1999), for example, has questioned the concept, claiming that some individuals are genuinely dependent on the help and care of others and are unable to reciprocate (Kroger,

2009). This could potentially be the case in the context of severe types of childhood epilepsy, with seizures and associated cognitive and behavioural issues limiting a child's independence and ability to be involved or care for themselves (Mu, 2008). Alternatively, Kittay, proposes the continued use of the term dependency to demonstrate the imbalance between individuals in terms of their need for support (1999; 2011), stating that: "independence is a fiction [...] all people are mutually dependent on each other" (1999: pp.268). In reconciling these two perspectives on interdependence and dependence, Fine and Glendinning (2005) argue that "to recognise 'interdependence' is not to deny but to acknowledge relations of dependence" (pp.612).

Thus, interdependency encapsulates the shared vulnerabilities and collective quest to care within a mutual and dynamic caring relationship such as those found in a family (child-parent) context. It includes key aspects important to both disability and childhood studies discourses as interdependency can assist in re-addressing power (im)balances often seen in a child-parent caring relationship (Morris, 1993; Kittay, 2011). Furthermore, it offers a fresh perspective on the debates around children and involvement by highlighting children's roles within caring relationships both at home and in clinical settings, through emphasising their capacity for agency (Cockburn, 1998). For example, quality healthcare for children, according to healthcare guidelines (e.g. Scottish Executive, 2007), is care that is co-produced by children, their parents, and healthcare professionals, with all working interdependently to co-create and co-deliver care (Botes, 2000; Coyne, 2006a). Accordingly, the complexity of interdependency, in conjunction with an ethic of care, provides the opportunity to explore the care practices and agency of children and parents in the context of childhood epilepsy (Brannen and Moss, 2003; McLaughlin and Clavering, 2012).

This chapter has, thus far, illustrated how the term family has previously hidden caring practices and relationships, as well as how care has been conceptualised by feminist and disability studies scholars. A further conceptualisation of care, namely Tronto's ethic of care, has been put forward as a manner in which care and care practices in the home can be fully examined. The concept of interdependency was also detailed, providing a complementary insight and means to explore children's, and parents, experiences and involvement in their care and caring practices.

4. Care and Childhood Epilepsy: In the home and clinic

In this section, the ethics of care approach and the concept of interdependency will be drawn on to explore care and caring practices in regard to childhood epilepsy treatment and management in the home and in a clinical setting.

4.1 Care at Home: Children, Parents, and Childhood Epilepsy

Through discussing various conceptualisations of care, distinction can be made between 'care as work, labour, and activity', 'caring about' children, and 'care as an ethical orientation' (Williams, 2004; Doucet, 2001). Unpicking this further, there has been great research interest in the last decade exploring care in terms of work-family balances for working parents (e.g. Harden and MacLean, 2012). Yet, there has been minimal examination of the context of chronic illness, in particular children's role and the child-parent relationship dynamic, raising questions as to how chronic illness care is prioritised within a family, how it is distributed, and how it is negotiated by children and parents through parenting and family practices.

In the context of childhood epilepsy and most chronic illnesses, the majority of health-related care predominantly takes place in the home, by individuals and their families on a daily basis, rather than being carried out in formal healthcare settings by healthcare professionals. As outlined in chapter one, children with active epilepsy must take anti-epileptic medications at regular times, ensure that their daily activities do not exacerbate the potential for seizures to occur or cause potential harm should a seizure occur, and if a seizure does happen those around them must be prepared to administer first aid where required (Appleton and Marson, 2009). From the point of an epilepsy diagnosis, parents (usually mothers) take responsibility for implementing and enforcing treatment and management regimens for their child, altering the child-parent caring relationship (Fine, 2005; Venter, 2011). This responsibility then progresses to a period when both the child and parents are involved, until ultimately the young adult assumes full responsibility and autonomy (Chappell and Williams, 2002). Shifts in responsibility are significant in the context of epilepsy, as 30% of children with epilepsy will need to continue taking medication into adult life (Appleton and Marson, 2009). These shifts in and sharing of, caring responsibilities characterise the changing nature of the caring relationship and how it adapts between children and parents.

Parents are legally and socially seen as the primary care-providers for their children (Bridgeman, 2007). Within this, parents are assumed to take (moral) responsibility for children's wellbeing, holding a duty to protect, and to provide and care for children (Fink, 2004; Such and Walker, 2004). In this regard, children's care in Britain is synonymous with parental responsibility, implicating notions of parental power, authority and control (Brannen and Moss, 2003; Wyness, 2013). Parenting roles evolves over the life-course, but can be especially acute in regard to childhood epilepsy and other childhood chronic illnesses (McLaughlin and Clavering, 2012). In line with policy and legal imperatives, many parents experience this responsibility on more or less unconditional terms, equating fulfilment of this obligation as good parenting (Wyness, 2013). Such a perceived moral imperative can influence parents' decision-making and autonomy regarding their children (Churchill, 2011). These parenting practices illustrate an everyday ethic of care underpinning: the motivation and sensitivities to the welfare needs of children, as well as the relational competences, and exchanges of resources like time and emotional labour (Sevenhuijsen, 1998; Churchill, 2011).

What constitutes parental responsibilities and caring parent-child relationships, is context-specific and dynamic (Churchill, 2011). Parenting in the context of childhood epilepsy (or other childhood chronic illnesses/disabilities) may be considered different when compared with other parent-child caring relationships (McLaughlin, 2006). Childhood chronic illness can strain and require additional moral dimensions to parenting practices as new forms of 'care' (treatment and management approaches for instance) are needed (McLaughlin and Clavering, 2012). For example, families with chronically ill or disabled children experience a greater degree of public judgement and discourse regarding their lives (McLaughlin, 2006; McLaughlin and Clavering, 2012). With successful parenting connected to children's future potential, the presence of childhood chronic illness can cause uncertainty (McKeever and Miller, 2004; McLaughlin, 2006). Parenting in this situation is under a more penetrating gaze, with increased levels of (often desired) medical advice and guidance on how to raise their child. Furthermore, the more that this 'different circumstance' is emphasised (or seen), the more that parents of ill and disabled children (along the children themselves) are perhaps constructed as 'failures' by wider society (James, 2007). This can fuel perceptions of children with a chronic condition as more vulnerable and in need of great adult protection (James, 2007). It is vital, therefore, to explore the (self-

and other-ascribed) moral obligations and responsibilities of parents within the context in which they experience and 'do' and 'display' the associated care practices (Finch, 2007; Morgan, 2011).

Alongside their parents' contributions, children's contributions to care and the care relationship are also paramount. As outlined in section 2, sociologists of childhood have demonstrated children's competency and agency regarding their own illness, but little research has examined agency in the context of chronic illness care in the home (Harden et al, 2016). How children conceptualise and construct 'care' and the caring relationship, their role within these and the associated negotiations can provide insights into their wider experiences of illness (Moss and Brannen, 2003). This is especially paramount in the context of childhood chronic illness where there are often a number of individuals (parents and healthcare professionals etc.) involved in managing and treating the child's condition place (Coyne, 2006a; McLaughlin and Clavering, 2012). Brannen and colleagues (2000) illustrate children's active co-participation in their parents' care. Yet, they also demonstrate that parents and children are not equal partners (Brannen et al, 2000; Alderson et al, 2006). Children's capacities for bringing about change in their circumstances is limited by the extent to which the change fitted with the demands of parenthood, restrictions of the illness, and with particular constructions of childhood, age and transitions (Harden and MacLean, 2012).

The child-parent caring relationship is consequentially based on, conscious and unconscious, negotiations between children and parents, incorporating notions of autonomy, responsibility, and competence (Tronto, 1993). The negotiations are constantly reviewed and revised dynamically, taking into consideration adapting competences and levels of autonomy, to determine how the caring responsibilities are shared between children and parents. As with any negotiation, there can be a discord between perspectives. For example, children may experience their parents' care as both constraining and liberating, as parents seek to create a sense of independence in their children, but also to protect them from risks and danger (Murray and Barnes, 2010). Thus, everyday care ethics are constantly negotiated in relation to particular situations, relationships, and in the context of other (often competing) moral claims and social norms (Brannen et al, 2000).

4.2 Care and the Clinic: Children, Parents, and Healthcare Professionals

Developing an understanding of how children and parents negotiate chronic illness care in the home is only part of the picture, with a great deal of treatment and management care decisions taking place in formal clinical contexts. For childhood epilepsy, seizure activity, treatment, and associated developmental concerns are closely monitored by a team of paediatric neurology consultants and nurse specialists to ensure that the condition is managed appropriately with any adverse effects dealt with and mitigated (Appleton and Marson, 2009). Epilepsy care, thus, involves the child, parents, and an array of healthcare professionals. The role of children in such medical conversation is, however, often overlooked and under explored by social scientists (Tates and Meeuwesen, 2001), despite, as I note above, children having a widely-held right to be consulted and involved in their own care (Coyne, 2006a).

Questions regarding autonomy, competence and responsibility are replicated in discussions regarding children's involvement in formal health care (connecting previous sections above 4.2; Moore and Kirk, 2010). Healthcare professionals, as well as parents, hold key roles in the lives of children with chronic conditions (Koller et al, 2015), as both facilitators and restrictors to a child's agentic potential. For instance, they make decisions as to whether the child is 'able' or 'capable' to participate in discussions and to what extent and form this participation takes (Coyne, 2006a). These decisions are not necessarily taken by the child, reflecting adult frames of child conceptualisation.

A great deal of socio-medical research examining childhood chronic illness has operated on the basis that, children under the age of 12 years are not seen as capable of taking on responsibilities nor be actively involved in their own chronic illness care (Williams et al, 2007; Moore and Kirk, 2010; Sawicki et al, 2015). It is only at the point of adolescence that such research has deemed children, or young people, as able to begin taking charge of their own care (Thorne et al, 2003; Alderson et al, 2006). Many studies examining young people's involvement in their chronic illness care focus on adherence, concordance, and (non)compliance (Paterson et al, 2001; Thorne et al, 2003; Townsend et al, 2006).

Within this context, there has been little examination of how younger children (below 12 years) actively participate in negotiating roles and responsibilities around their care through agentic actions and behaviours, and how this is iteratively reappraised over time (Mayall, 2015; Curtis-Tyler et al, 2015). Exploring children's perspectives in this regard recognises and acknowledges children's increasingly emerging autonomy (Mayall, 2002). Of the research that has been conducted, children have shown strong experiential understandings of their condition, see themselves as key contributors of their care, and appreciate adults engaging with them in ways that acknowledge this (Prout et al, 1999; Curtis-Tyler, 2012). Alderson and colleagues (2006) also demonstrated that from approximately 4 years of age, children started to understand the principles and take responsible moral decisions about the management of their diabetes, with their competence to consent developed through their experience rather than age. Moreover, Coyne (2006a) concluded that children's emerging autonomy, and agency, needs to be fostered by both parents and healthcare professionals. Both have a significant influence on whether children's efforts to participate, and be agentic, are facilitated and supported in a clinical setting (Coyne, 2006a; Curtis-Tyler et al, 2015). This also connects with how children's knowledge and expertise of their chronic illness is evaluated by healthcare professionals and parents (LeFrancois, 2007).

Much of the research exploring children's involvement in clinical and healthcare contexts has illustrated the differences in the distribution of authority, accountability, and responsibility in child consultations (Trnka, 2014). In the triadic-interaction between child-parent-healthcare professional in the context of paediatric clinical appointments, each will bring certain assumptions, experiences, and conceptualisations that will influence the clinical encounter (Tates and Meeuwesen, 2001). These preconceptions, and associated power differentials, can lead to the forming of coalitions (Charles et al, 1997). Coalitions are formed around the relationships, or partnerships, that develop in clinic appointments and around decision-making. In examining the forming of coalitions in paediatric appointments, Gabe and colleagues (2004) identified two primary examples. Firstly, the desire of a parent to see some resolution to a child's symptoms may result in a coalition between parent and the doctor, in pursuit of a particular treatment, regardless of the child's own preferences. Separately, it can be that the doctor forms a coalition with a child

(patient) to resist pressure from a parent to follow a particular course of action, giving the child some time to come to their own decision.

Children have shown, and self-reported, contributing to their clinic appointments (Garth et al, 2009), however, there were found to be limitations to their involvement. The partnership was shared exclusively by parents and paediatrician. In Bendelow and Brady's (2002) study on compliance of ADHD medication in children, they noted that children were aware that healthcare professionals did not perceive their view as important as that of the 'experts' – parents or healthcare professionals. Thus, despite legislation and healthcare policies, children are not seen as equals within the healthcare partnership; their agentic potential has gone unrecognised or noticed (Gabe et al, 2004). Parents and healthcare professionals can (and do) still take the lead, monopolising discussions and decisions; restricting children's agentic opportunities and potential (Williams et al, 2007; Coyne, 2006b). This has often led to the rise of the parent-expert who negotiates their child's care and makes decisions on their behalf (Trnka, 2014).

Through their systematic review, Joseph-Williams and colleagues (2014) further illustrated the need for (adult) patients to have knowledge and power in order to participate in shared decision-making in clinic appointments. Moreover, many (adult) patients currently cannot participate in shared decision-making due to this lacking, rather than suggesting that they choose not to participate. This finding encourages a more depth exploration of the nature of children's agency in these contexts. As Gabe and colleagues (2004) equally state (amongst a growing number of researchers), whilst adult and healthcare professional power has been shown to have a bearing on children's experiences, it would be wrong to suggest that children cannot and do not exercise agency in a variety of ways and for different reasons (Garth et al, 2009; Joseph-Williams et al, 2014). How such enactment is viewed, facilitated and potentially restricted by parents and healthcare professionals in the clinical setting has, however, not been examined.

5. Embedding Chronic Illness

How children, and relatedly parents, experience their illness and its care does not exist in a vacuum or independently: the social, cultural, and personal context will all

influence the moral dimensions (e.g. the value-laden responses to symptoms or treatments) of the illness (Charmaz and Rosenfield, 2010). Explorations of the consequences of chronic illness and the steps taken by individuals and their support systems to mitigate its effects, and its associated care, have come to occupy a significant space within the field of sociology of health and illness (Charmaz and Rosenfield, 2010). In the literature, key concepts have been used widely to explore the experiences of individuals (initially, and primarily, adults) across a range of chronic illnesses, including biography, normalisation, and stigma. Each of these concepts will be explored in turn to further understand their application to children, and parents, experiences of childhood epilepsy and its associated care.

Biography is a valuable aspect of understanding chronic illness experiences, by emphasising the meaning and context in which chronic illness is located it centralises the individual and how illness can, and does, influence their life (Bury, 1991). An individual's biographical context incorporates both their structural positioning (such as gender and age) and their social relationships, including family and healthcare professionals (Lawton, 2003). Further, it is open to influence and manipulation by others and changing situations (Zinn, 2005; Bray et al, 2014). In the context of family, the biographies of parents become entangled with those of their children's (Chamberlayne and King, 1997; Bray et al, 2014). It is unsurprising then that there has been a wealth of well-developed literature and research using the concept of biography as a lens through which to explore and analyse chronic illness experience for individuals and families (Bury, 1982; Bury, 2002; Williams, 2000).

The most noted use of 'biography' is through Michael Bury's conceptualisation of biographical disruption (Bury, 1982; see also Williams, 2000). Bury contends that the structures of everyday life and the forms of knowledge underpinning the experiences are disrupted with the onset and diagnosis of an illness, especially chronic illness (Bury, 1982; 2002). The concept highlights the complex and multi-faceted manner through which the experience of chronic illness can lead to a (sometimes fundamental) rethinking of an individual's biography and self-concept, influencing many dimensions of their lives.

The idea of biographical disruption has proved durable, being studied in the context of many chronic and terminal illnesses over the last three decades (Williams, 2000;

Pierret, 2003). It has also been the subject of debate and critique. One critique is the lack of consideration given to the context and timing of the onset of illness. Disruption is not universally and uniformly experienced by those even with the same condition. Demographic differences, age of onset, and severity of the condition all influence how chronic illness is experienced (Williams, 2000; Sanderson et al, 2011).

Few studies have focused on childhood chronic conditions, with questions being raised regarding the applicability of biographical disruption in children potentially too young to remember a time before the illness (Williams, 2000; Pierret, 2003; Williams et al, 2009). The limited discussion has suggested that the presence of a condition from birth or early childhood could result in the illness becoming a 'normal' part of the child's life (Williams, 2000), perhaps illustrating that it is the long-term nature of an illness that influences how it is experienced by children and young people (Bray et al, 2014). Williams and colleagues (2009) have found biographic disruption relevant in younger age groups but in a more nuanced form than for adults, proposing that biography is influenced by illness, simply not to a significant, 'disruptive', degree.

Subsequent research has sought to expand biographic concepts beyond the narrow view of disruption to incorporate alternative strategies, context, and wider influences (Sanderson et al, 2011). For example, the term 'biographical abruption' has been used to convey the sudden 'breaking off' of life on diagnosis of a terminal condition, such as motor neurone disease (Locock et al, 2009). In contrast, 'biographical reinforcement' has been coined to express the reinforcing of an already perceived, collective and individual biography and experience (Carricaburu and Pierret, 1995). Furthermore, 'biographical continuity' or 'flow' has been used to describe how in some situations, especially in older age, illness is seen as a natural progression, or when previous illness experience suggests the current illness is to be expected or was anticipated (Pound et al, 1998; Faircloth et al, 2004). Such expansions of biographic concepts demonstrate the value in considering individuals' wider biographies and contexts, in examining their chronic illness experiences.

When reflecting on childhood epilepsy, the expanded notion of 'biographical repair' is especially thought-provoking. Biographical repair, developed from the notion that a diagnosis of a chronic illness can form a disruption to an individual's imagined life trajectory (Sanderson et al, 2011). It is, however, not a one-off disruption that must be

adjusted to, but rather a repeated cycle of confronting and re-adjusting to each phase of the illness which incorporates periods of symptom intensity in to daily, 'normal' life (Locock et al, 2009; Sanderson et al, 2011). Sanders and colleagues illustrated a 'repairing' biography in individuals' with osteoarthritis; at times, their condition was an accepted part of their biography, but it also caused occasional disruption with bouts of pain and physical limitations (Sanders and Rogers, 2007). This iteration of the biographic concept could be applicable to individuals' accounts of epilepsy: the unpredictability of seizures, the periods of having minimal or no symptoms whilst on anti-epileptic medication, and the safety measures put in place to minimise injury and accidents (Kerr et al, 2011).

Biography and its associated elaborated concepts can provide a wealth of insight into the meaning attributed to chronic illness and its influence on an individuals' sense of self and their wider social relationships. Furthermore, such biographical approaches offer a manner in which to explore personal responses to chronic illness and associated care situations (Chamberlayne and King, 1997). Despite the continued neglect of exploring children's perspectives in this regard, there is scope to apply biographic concepts when examining childhood epilepsy. Biographic concepts enable a detailed exploration of how epilepsy is embedded into a child's sense of self, how this changes in different contexts, and how it can be influenced by others, including parents. It is, therefore, a thought-provoking and valuable orientating concept for capturing a unique insight into children's experiences of having epilepsy.

The presence of chronic illness can create a new sense of normality, as children and their families make adaptations and compromises to their lives in order to accommodate a diagnosis of chronic illness (Bury, 1982; Williams, 2000). Treatment and medication regimens form part of a 'new' everyday life (Bray et al, 2014). Normalisation is closely related to biography, through its conceptions of a normal life whilst also drawing attention to the bodily experiences and normalising of symptoms over time (Sanderson et al, 2011). For example, within biographic continuity, flow, and repair (from the previous section), the effects of illness are normalised by individuals and their families (Pound et al, 1998). Normalisation has emerged across chronic illness literature, providing insight into how individuals' and their families seek to manage, understand, and live with chronic illness.

Weiner (1975) first defined normalisation in individuals with a chronic illness as behavioural attempts to maintain a 'normal life', including: using strategies to hide signs of illness (covering-up), maintaining a normal lifestyle (keeping-up), and carrying out fewer activities at a normal pace instead of failing to achieve everything at a heightened pace (pacing) (Weiner, 1975). Knafl and Deatrick (1986) developed this idea and created a concept analysis, which illustrates the steps of normalisation, on a family level, in four main processes: firstly, the defining of family as essentially normal; secondly, acknowledging the existence of deficiencies; thirdly, understanding the social consequences of the situation as minimal; and finally engaging in behaviours designed to demonstrate normalcy to others (Knafl and Deatrick, 1986; Deatrick et al, 1999).

Building on this further, Carole Robinson suggested that normalisation could be further conceptualised as a camera lens, or a 'normalcy lens' (Robinson, 1993). Robinson argued that one-way families managed a chronic condition was to use an interpretative lens through which family life could be constructed as 'life as normal' by focusing on the ongoing normal aspects of the situation (Robinson, 1993; Williams et al, 2009). This lens enables interaction with others, outside the family, based on the view that the child is 'normal' (Robinson, 1993; Deatrick et al, 1999). This collective nature of the normalcy lens captures the shared dimension of in childhood chronic illness: due to the guaranteed involvement of key family members in care and management of the illness (Williams et al, 2009). Accordingly, normalisation recognises the ways in which family members' subjective definitions of the illness situation shape their routine and everyday life (Williams et al, 2009). With the routines of treatment and management becoming naturally ingrained in family life, it becomes almost invisible to children and their parents (DeVault, 2003; Williams et al, 2009).

There have been a number of studies exploring how children and families perceive chronic conditions and how it is incorporated into family life using normalisation. A common theme through parents' and children's accounts is the concern of being viewed as *not* different by peers and sustaining feelings of *non*-difference (Williams et al, 2009). This could be due to chronic illness being seen as a threat to the 'expected' or 'normal' childhood, as discussed previously (Prout et al, 1999; Mayall, 2002; Brady et al, 2015). Parents attempt to normalise their child's condition to continue displaying a normal family and to attempt to give their child a 'normal' life (Prout et al, 1999;

Finch, 2007). Children's priorities and autonomy might, however, conflict with these values, views, and practices of parents disrupting a potential normalisation 'script' (Fisher, 2007; Bray et al, 2014). Consequently, it is important to examine both parents' and children's accounts of living with childhood epilepsy to better understand the negotiations of everyday family and care practices.

In exploring normality with children and young people with cystic fibrosis, Williams and colleagues (2009) found that young children with relatively asymptomatic illnesses or those whose illness trajectory was highly incremental did not experience a significant struggle to create or maintain a personal form of normality. The greatest threat to normalcy was considered to be from the impact of time-consuming treatments on personal identities. Furthermore, older children were more aware of social, as opposed to personal, definitions of normality, and resultantly engaged in behaviours to create and maintain an un-affected identity to peers and wider society (Williams et al, 2009). In concluding, Williams and colleagues (2009) stated that maintaining normality within a family is the result of continual biographical revisions and anticipation of future illness progressions. Continual biographical revisions are subsequently required by children and young people to maintain a personal and social sense of normality (Williams et al, 2009).

Thus, as a theoretical concept normalisation captures how individuals view and conceptualise their chronic illness and the manner in which they chose to be presented, or not presented, it as part of their biography. Furthermore, it questions how illness impinges on daily life for children and parents, and how these effects are mitigated and negotiated. Normalisation, therefore, has the potential to provide a lens through which to explore the everyday experiences of children with epilepsy and their families.

In presenting (implicitly or explicitly) a normalised self and biography, however introduces the concept of stigma. Stigma uniquely alters perceptions of normalcy and raises questions of difference (Coleman-Brown, 2016). As Goffman detailed, 'stigma is equivalent to an undesired difference (Goffman, 1963). Most people do not want to be perceived as different or 'abnormal', so normalisations strategies, as detailed above, can be used to disguise or hide any signs of difference (Scambler, 2004; Coleman-Brown, 2016). However, in the context of chronic illness (such as epilepsy),

the presentation of normal can be challenging (described in the introduction through the 'in/visible paradox'). The social context in which the chronic illness presents and is inferred can influence its experience and impact on the individual and their wider support systems – whether positively or negatively (Charmaz and Rosenfield, 2010). Goffman (1963) argued that stigma is defined and enacted through social interaction. It is socially constructed in and through social relationships, lying in the social rules which guide behaviour defining what is seen as acceptable, customary, 'normal' or expected (Benson et al, 2016). As pointed to within the introduction, epilepsy has the potential to break social norms and normality through unpredictable seizures and the paradox by which it can appear invisible until such seizures occur. This is perhaps why, as a condition, social scientists have used the condition to further explore stigma concepts.

The historical context of epilepsy, as a predominantly unknown illness, has reinforced negative stereotypes of the condition on a societal level. Theories of epilepsy as contagious and with connections to lunacy can be traced throughout historical medical texts (Schiender and Conrad, 1983), with early biomedical explanations of epilepsy linking into aggressive or criminal behaviour has perpetuated a negative association of epilepsy. Coupled with the fear and misunderstandings that can be invoked for those witnessing a seizure, either in terms of concerns of safety or confusion and perceptions of deviant behaviour, epilepsy has many negative associations. Such misconceptions and interpretations of seizures, and the condition more generally, have influenced how epilepsy is experienced by individuals diagnosed and by wider society. Recent studies have found improvements in societal attitudes towards the condition, though levels of knowledge have remained static (Jacoby, 2002). In a UK survey of 1,600 randomly selected respondents, Jacoby and colleagues (2004), found that over half agreed that people with epilepsy are treated differently (social avoidance and exclusion). Remnants of these 'old' ideas, continues to inform popular concepts of epilepsy.

Although driven in-part by social constructions, there are further individual-level components that are influential to stigma. Goffman (1963) distinguished between two types of stigma that individuals living with epilepsy may experience: enacted and felt. Enacted stigma refers to individual experiences of actual episodes of discrimination and/or exclusion solely due to the possession of the discrediting attribute (i.e.

epilepsy; Goffman, 1963; Scambler, 2004). Felt stigma is instead regarded as a process of self-stigmatisation whereby the individual experiences shame as a result of having discrediting attribute (e.g. negative reactions to the disclosure of epilepsy or feelings of differentness), and consequently fears encountering enacted stigma. Building on these, Jacoby and Austin identified that epilepsy-related stigmatisation operates on three primary levels: institutional (indirect expressions of different treatment of those with epilepsy), interpersonal (being treated differently within interactions with others; enacted) and internalised (felt within the person with epilepsy, reflecting their feelings, thoughts, beliefs and fears of being different) (Jacoby and Austin, 2007).

Two of the most prominent studies exploring epilepsy and experiences of stigma (Schneider and Conrad, 1983; Scambler and Hopkins, 1986) found similar differentiations between the types of stigma. Through their extensive interviews Schneider and Conrad (1983; Scambler and Hopkins, 1986) found that many adults with epilepsy believed that their condition was stigmatised both by themselves and by others, indicating an individual and societal level stigma. Scambler and Hopkins (1986) furthered this work, through their own interviews, developing a stigma model of epilepsy, further drawing out aspects of enacted and felt stigma. Both studies emphasised that the stigma associated with epilepsy meant that those with the condition carried a burden of feeling that they were in some way 'spoiled' (Schneider and Conrad, 1983). From across the stigma research, seizures are seen as a threat to a sense of self, as there was seen to be no control over them. As Kerr (2012) more recently summarised seizures can result in stigmatization and social exclusion, with detrimental effects on an individual's confidence and self-esteem. A wealth of international research has also illustrated the variety and pervasiveness of cultural influences that affect how epilepsy, and seizures, are viewed, interpreted, and resultantly the stigma that they can induce (e.g. Tran et al, 2007; Shafiq et al, 2007).

There are few studies directly examining children with epilepsy and their perception of stigma (Benson et al, 2015). This is despite a wealth of quality of life studies suggesting that stigma is experienced and negatively influences children's quality of life and socialisation (Jacoby and Austin, 2007; Jacoby, 2008). Cutting across many of the challenges of living with epilepsy was, by children and parents, the desire for a 'normal' childhood and for normalcy indicating an implicit sense of stigmatisation of epilepsy (Harden et al, 2016). Similarly, among the few studies exploring children's

epilepsy-related stigma experiences was the concern of how others perceived them and by extension their epilepsy (Jacoby and Austin, 2007; Benson et al, 2016).

Parents have a fundamental role in explaining and incorporating a child's chronic illness into both their own and their child's lives. What they chose to say and share is inextricably linked to their child's understanding of the condition (Benson et al, 2015; Benson et al, 2017) as well as how children perceive themselves in relation to their condition (Benson et al, 2017). As Farrugia (2009) demonstrated, parents of children with autism spectrum disorder experienced considerable enacted stigma, but successfully resisted felt stigma by deploying medical knowledge to articulate unchanged sense of self (Farrugia, 2009). Consequently, how parents engage children in discussions about childhood epilepsy plays an influential role in epilepsy-related stigma. For example, limited familial epilepsy-related discussions can be an implicit expression of stigma associated with epilepsy as a condition (Benson et al, 2016; O'Toole et al, 2016). Similarly, where parents do discuss or convey information about the condition may (consciously or unconsciously) be interpreted in negative or shameful ways (Jacoby and Austin, 2007; Benson et al, 2016). In the same way that children may learn to stigmatise without ever grasping 'why' they do so, they may also feel the shame and fear associated with felt stigma without grasping 'why' (Benson et al, 2016).

However, as Rood and colleagues (2014) noted when exploring different perceptions of epilepsy-related stigma, there can be poor consistency across children and their parents' responses to perceptions of stigma. Their findings illustrated that while children with epilepsy initially perceive epilepsy-stigma at diagnosis, their perception of stigma decreases over time (Rood et al, 2014). This was unlike their parents, where stigma was perceived consistently (Rood et al, 2014). Rood and colleagues' (2014), findings reflect previous research on the discord between children and parents' reporting on quality of life (Shute, 2005; Gannoni and Shute, 2010; Harden et al, 2016). Thus, the differences between children and parents' epilepsy experiences can result in different meanings, associations, and implications of a diagnosis of epilepsy being made.

Accordingly, these different experiences and associations of epilepsy can influence how treatment protocols and management strategies are perceived and dealt with in

daily life by children and parents. The perception of epilepsy-related stigma has already shown to be problematic for maintaining and adhering to prescribed medication regimes for those with epilepsy (Chesaniuk et al, 2014). Thus, exploring concepts and experiences of stigma can provide further insights into children and parents' experiences of the condition, but also how they manage epilepsy-associated care and potentially children's involvement within it.

In sum, children and parents' experiences of epilepsy could be influenced through their attempts to mitigate the consequences of the condition and its care. This could be through attempting to protect their own (and their child's) biography, appear 'normal' and reduce the scope and potential stigma that having epilepsy still entails. The concepts of biography, normalisation, and stigma thus offer further means to examine children and parents' experiences of their epilepsy and its associated care.

6. Summary

This chapter has reviewed the literature on children and childhood, agency, family, care, and chronic illness. The literature has further illustrated how children's own experiences of childhood illness (and epilepsy) and their role in home and clinical care practices are under-represented in research. The sociology of childhood as a body of literature offers a unique position to examine children's agency, roles, and negotiation within their experiences and involvement in epilepsy treatment and management. How others, namely parents and healthcare professionals, understand children's agency and capacity to be involved influence children's agentic opportunity.

The broad topic of care was explored through examining theoretical underpinnings of family, feminism, and disability studies, specifically drawing on the ethic of care and concept of interdependency. The various conceptualisations have highlighted different perspectives of care, the caring relationship, and associated responsibilities. Furthermore, from examining care from these perspectives it has illustrated a number of interwoven dimensions that are influential in shaping its conceptualisation in different contexts. Namely, how care is experienced and normalised in everyday life by children and parents, how care can be viewed as a means of protection and as a responsibility for both, and finally how they each negotiate care and caring practices and the influence of power dynamics (and imbalances) within it. By exploring each of

these dimensions it provides a way to explore children's, and parents, experiences and involvement of childhood epilepsy care practices both at home and in a clinical setting. Moreover, the theoretical concepts of biography, normalisation and stigma offer a significant manner through which to explore care in the context of epilepsy. Each concept helps orientate and sensitise analytical attention to differing dimensions of children's and parents' accounts and experiences of epilepsy and involvement in its associated treatment and management regimes.

Based on the literature review detailed above, this research therefore aims to gain broader insights of children's experiences of childhood epilepsy and their agentic involvement in the treatment and management of their condition across both the home and clinical settings. Within this, how parents shape and support children's involvement in and across these settings will also be examined. These overarching aims were refined into three key research questions guiding the research study:

1. What does having epilepsy mean to children?
2. To what extent do children perceive themselves as actively involved in the management and treatment of their epilepsy within the home and clinical settings? In what ways do parents' shape and support children's involvement?
3. What are the support and information needs of children with epilepsy?

The following chapter outlines the research design, methodology, and ethical considerations of the study.

Chapter Three: Research Design, Methodology, and Ethical Considerations

1. Introduction

The discussion of the literature presented in chapters one and two identified research gaps and areas for exploration regarding children's experiences of childhood epilepsy and their involvement in its treatment and management. In this chapter, I present a critical, reflexive account of my research design, methodology and practice, as well as a discussion of the core ethical considerations for this study. Table (Two) provides an overview of the research:

Study Design	Qualitative research.
Ethical Approvals	NHS Research Ethics Committee and NHS Research and Development approvals granted.
Sample Size	23 children and 31 parents.
Summary of inclusion criteria	<ul style="list-style-type: none">- Child with active epilepsy aged 7 to 16 years.- English was their first or primary language.- Child must have been diagnosed with epilepsy at least one year ago.
Summary of exclusion criteria	<ul style="list-style-type: none">- If the child has febrile seizures or provoked seizures only.- If the child has an unconfirmed diagnosis of epilepsy or diagnosed under 1 year ago.- If the child has had a formal, or are waiting for, a psychological assessment and deemed to have an IQ lower than 70 (+/- 2 Standard Deviations).
Recruitment	After fully briefing the Paediatric Neurology teams of the aims, inclusion/exclusion criteria, and designs of the study, the initial approach to appropriate children and their parents was made by

	the child's neurology consultant. Those participants who opted-in were then contacted. Consent was obtained in a follow-up meeting.
Research design	<p>Two interviews with children and their parent(s), and an observation of a routine clinic appointment (occurring before the second interview). These interviews were used to explore their everyday experiences of childhood epilepsy, its treatment and management and their involvement within it. There was on average four and a half months between the first and second interview.</p> <p>A range of tools were used in the first child interview (spider diagrams, magnetic family and friends, and comic book vignettes), the first parent interview (comic book vignettes), and the second child interview (pots and beans).</p>
Data Analysis	Thematic approach.

Table Two: Summary of the research conducted.

This chapter will first explore how the key threads of the literature review have shaped the theoretical underpinnings of my research design and methodology. This is followed by a critical exploration of the central issues to the design of the research: researching children's lives, generating multiple inter-generational perspectives and the management of such perspectives, and the ethical considerations for the study. Attention will then move to the practical aspects of the study including: the demographic details of the children and parents involved in the study, and the sampling and recruitment strategy adopted to recruit them. The research methods used and a reflection on the process of collecting the data will then be detailed. Finally, the analytical approach adopted will be described.

2. Research Design and Methodology

The research aims and questions detailed at the end of the literature review articulated the focus of the study and consequently strongly influenced the research

design and methodologies chosen to address the questions. This section will explore the theoretical foundations of these aims serving to contextualise the design and methodological decisions.

2.1 Foundations of the Research Design

As highlighted from the introduction (chapter one) and literature review (chapter two), the study was designed to draw out a sociological understanding of children's own experience and involvement in their treatment and management. Alongside this, for the study to be able to provide insights for clinical practice, I felt it was important to reflect on how the research design adopted complements the independent yet interconnected clinical disciplines in which childhood epilepsy has been more frequently examined. This context has influenced the theoretical foundations, and design and methodology of the research study, as well as shaping my position as a researcher.

In designing any research study, it is essential to acknowledge such underlying influences and assumptions. Influence can emerge from the ontological and epistemological positions adopted as a researcher (Creswell, 2003). The ontological position reflects beliefs regarding the nature of the world, and connectedly, the epistemological position taken mirrors how it is possible to know and seek understanding about the world (Marsh and Furlong, 2002). By examining the underlying assumptions and influences created by these positions, the study design can be rendered more robust (Lewis and Lindsay, 2002), since such assumptions provide the foundations upon which the explorations of the study are built. Thus, it is important to be critically reflective on the stance adopted from the outset, and to remain so during the research process.

This study and my position as a researcher are situated within an interpretative realist position. The realist positioning puts forward an ontological reality which exists independently of me, my research, and the study's particular area of interest (Ormston et al, 2014). The 'reality' this study sought to explore was the variety of features, activities and practices of having and living with childhood epilepsy. Specifically, the activities around administering and taking medications, having and managing seizures, and interactions with healthcare professionals and attending clinical

appointments. These components of reality provided an opportunity to explore children's (and parents') everyday experiences of having, and living with, childhood epilepsy and their involvement and understanding of care in this context.

Of critical importance, and further reflecting an interpretivist frame, was children's and parents' own interpretations of these features, activities and practices of epilepsy (Mason, 2002; Ormston et al, 2014). I believe that the nuances of realities are only accessible through the perceptions and interpretations children, and their parents, choose to share (Ormston et al, 2014). Accordingly, there is considerable value in attaining children's (and parents') own interpretations, with their varying vantage points offering different views and understandings of their epilepsy activities and practices. This, additionally reflects my belief in directly attaining children's views and perspectives, rather than utilising proxy assessments.

Through this interpretative realist position, this study sought to capture these diverse and multifaceted realities of childhood epilepsy offered by children and their parents. Alongside this, the context and circumstance of these realities was maintained, allowing nuances of different interpretations of realities to be explored across and between accounts (Mason, 2002; Maxwell, 2011). Accordingly, it is the aim of the research to capture the realities of everyday experiences of epilepsy (medication, seizures, and clinic visits) and children's involvement within it, in all the complexity and depth offered by children and parents.

As noted, it is vital to remain reflexive throughout the research process from design to analysis (Berger, 2015). Reflexivity, or reflexive thought, refers to a continual internal dialogue and critical self-evaluation of the position held as researcher, as well as the active acknowledgement and explicit recognition that this position may affect the research process and outcome (Mauthner and Doucet, 1998). Thus, a researcher must make conscious and deliberate efforts to be attuned to identifying potential or actual effects of personal, contextual, and circumstantial factors that may assist or hinder the process of constructing meanings and carrying out research (Berger, 2015). Given this, who I am as a person (as well as a researcher) was, and continues to be, important. My position as a researcher with my own experiences of health and illness had implications for how I approached and constructed the study design, data collection process, and analysis. Additionally, how I was viewed by the children and parents'

involved in the study was equally important and influential in our interactions, forming an important aspect of reflective thought (D'Cruz et al, 2007). I am neither a parent nor diagnosed or living with epilepsy nor have I experienced chronic ill-health. Yet, my experience of having my own medical issues and interactions with assorted healthcare professionals and hospitals during childhood has shaded how I perceive and draw interest from the subject matter explored. Resultantly, my reflective thoughts are threaded throughout this chapter, and again, in discussing the findings presented.

Providing an additional dimension to the theoretical underpinning, the study was further informed by conceptualisations of children emerging from the sociology of childhood (as discussed in more depth in chapter two). The core imperatives of adopting such a theoretical stance to researching children puts forward that children should be studied for and in themselves and not simply as a means of understanding an adult world or for simply addressing 'adult' concerns (Gallacher and Gallagher, 2008). Adopting such a stance sits slightly uncomfortably beside clinical constructions of children which, contextually, also provided an additional dimension to the research aims and questions put forward. As discussed previously (chapter two), in clinical settings children (in general) are often viewed in regard to their developmental stage and positioned as unable to report accurately on their own health and lives (Mayall, 1998; Balen, 2006). Although this view has begun to shift, it remains novel in such settings to engage children, themselves, in research regarding their own lives and illness (Balen, 2006). As this study was seeking to produce clinically relevant outcomes it was important to acknowledge both of these differing constructions of children and childhood (Berger, 2015). These theoretical underpinnings have key implications when researching children and the influence this can have on the whole research process, including: design, methods, ethics, participation, and analysis (Lewis and Lindsay, 2002). Thus, in order to adequately capture children's perspectives, critical reflexive thought is particularly pertinent when designing and carrying out the study (Tisdall et al, 2009).

To further attune my research design to the specifics of the study, during the first year of my PhD I attended many epilepsy clinics, run as part of the paediatric neurology service in central Scotland. This provided the opportunity to build a practical foundation to my own learning, as well as contextualising and embedding the

research I was reading and thinking about. During this time, I spoke with consultants, Epilepsy Specialist Nurses (ESN), and - importantly - children with epilepsy and their families. Speaking with all of these individuals provided initial insights into their experiences of epilepsy, how they describe and discuss epilepsy, and how they feel talking to someone else about it. The insights from the healthcare professionals were also valuable to understand their perceptions of the research priorities for childhood epilepsy. I observed a wealth of children's clinic appointments to see first-hand how they were carried out and what types of discussions took place. This provided the opportunity to examine whether my research questions could be explored using further observations of the appointments as part of my research design. All of these interactions provided additional context for my reflections on and engagement with the literature I had been exploring, informing my developing research ideas and shaping the study design. It was through these reflections that I came to adopt an interpretive realist stance, thus this approach was embedded throughout the research design process.

Given the theoretical underpinnings of the study (i.e. interpretative realism and insights from the sociology of childhood), a qualitative research methodology was chosen. Quantitative tools, including questionnaires have been extensively used in childhood epilepsy research in particular to gauge measures of quality of life, as was discussed and critiqued and in the literature review (chapter two; Apers et al, 2013). A quantitative approach would be problematic when researching the meanings children attach to them and how they make sense of their experiences of childhood epilepsy because they provide limited scope for exploration outside the initial focus of the research tool (Smith et al, 2000; Bell, 2007; Greene and Hogan, 2005). Consequently, I adopted a qualitative approach, which provides a means to reveal insights and understandings of children's and parents' social worlds through exploring the sense they make of their circumstances, their experiences and perspectives (Silverman, 2011). The flexibility and scope of qualitative methods allows a range of topics to be explored, trends in thought and opinions to be uncovered, and to dive deeper into what emerges, even when the import of aspects of the data may not have been immediately apparent earlier in the research process (Green and Thorogood, 2009; Carter and Ford, 2013).

2.2 Research Design – Researching Children

Much of the research designed to involve children has developed alongside the sociology of childhood and its underlying philosophies (Carter and Ford, 2013; Moran-Ellis, 2010). Within this, various approaches to carrying out research have developed. These include: a shift in methodological emphasis to participatory research methods, the development of multi-method approaches, and the creation of 'child-friendly' research tools (Punch, 2002; Fargas -Malet et al, 2010). In this study, I sought to access children's experiences in ways that would best draw out their understandings and meanings through prioritising their participation in the interview process involving the use of research tools to encourage and enable (all) participants to "create inclusive accounts using their own words and frameworks of understanding" (Pain and Francis, 2003, pp:46).

As Greene and Hill (2005) described, in order to capture children's perspectives and experiences accurately researchers should be open to using, or adapting, methods to suit children's individual level of understanding, abilities, and interests (Greene and Hill, 2005). With this aim, a plethora of adapted research tools have been created, including: drawing-to-tell activities (e.g. Heaton et al, 2005), photographs taken by participants (e.g. Zartler and Richter, 2014), sentence completion and writing (e.g. Morrow, 1999), walking tours (e.g. Anderson, 2004), and ranking exercises (e.g. O'Kane, 1998). The inclusion of additional tools in the design of interviews offers children different ways to communicate their experiences and generate their own data in meaningful and interesting ways in all their breadth and diversity (Christensen and James, 2008; Crivello et al, 2009; Carter and Ford, 2013). This can be particularly useful in making it easier for children to express sensitive topics and more critical views, as well as providing a different way to discuss difficult topics (Mayall, 2002).

Employing additional research tools can provide a means to break down generational power imbalances between child (participants) and adult (researchers) (Packard, 2008; Prosser and Schwartz, 2006; Thomson, 2007). Additional, participatory tools can be useful in opening up possibilities for children to help create knowledge in a way that suits their verbal and cognitive skills (Harden et al, 2000; Punch, 2002). Such tools offer the opportunity to reduce the reliance on verbal or written language competencies, which children *may* struggle with as well as making the data-generation process *potentially* more fun (my emphasis; Greene and Hill, 2005). Yet, not all children are the same, nor may have similar competencies or interests, highlighting one critique

of such methods. The flexibility of these methods does, however, mean that they can be tailored to take into account differing ages and capabilities of participants, enabling wider participation (Christensen and James, 2008). Given this, it is important to reflect carefully on which methods enable children to answer their research questions, while retaining flexibility that takes account of the status, context, and needs of individual participants (Harden et al, 2010).

A further critique reminds one that adopting such tools cannot offer a 'fool-proof' and child-centred approach to including children in research (Zartler and Ritcher, 2014). Instead, they are still just as problematic and ethically ambiguous as any research design and methodology (Gallacher and Gallagher, 2008). Additional concerns have been raised as to whether 'more' tools are necessarily better (Darbyshire et al, 2005). Further, the empirical base of what children think and feel about being involved in research using these tools remains weak, underscoring a need to be reflexive on their use (Zartler and Ritcher, 2014). Thus, as I considered which research tools to adopt, I reflected carefully, critically and conscientiously on their implementation, and whether they would enhance the study.

James (2007) warns of using such 'child-friendly' methods, stating that there is a tendency to slip into arguments of trying to represent the authentic or realistic voices of children. These arguments risk simplifying and reducing the complexity of children's agency, disempowering them and their contributions (Spyrou, 2011). This concern connects with my epistemological position, interpretivist realism – I recognise the critical importance of children's own interpretations and perceptions of their epilepsy and its treatment and management and believe that their vantage point yields a different, unique understanding (Ormston et al, 2014). Through this study, the aim was to capture children's reality, in all its complexity and depth, and (vitality) in their own words. By using additional tools, I hoped to create an environment to make children feel able and comfortable to provide these insights. Thus, through their contributions, a broader picture would be elucidated. It was not the use of tools themselves that gave 'voice' to the children, but rather their inclusion that encourages their 'voice', particularly given the potential sensitive nature of the research.

Reflecting these points, I chose to employ multiple tools as part of the two interviews with children and the first interview with parents. A more detailed exploration of each

tool is detailed in section 5 as I describe the data collection process. I felt using multiple tools allowed complementary insights and understandings of children’s experiences to be explored, which I considered may have been difficult to access through reliance on a single (inflexible) method of data collection (Darbyshire et al, 2005). Additionally, I felt their inclusion would make children’s participation in the interview process more attractive and provide alternative ways to respond to questions and introduce topics for discussion. The tools were always introduced as something flexible that children could engage or not engage with as they chose, never as something they must complete. They were also not regarded as data per se, rather a facilitator for discussions. The specific tools used in each interview are detailed in the below table (three); how they were implemented is discussed in section 5 below.

Interview One with Children:	Spider diagrams. Magnetic families and friends (ranking activity). Comic book vignettes.
Interview One with Parent(s):	Comic book vignettes (the same as were used with children).
Interview Two with Children:	‘Pots and beans’ (ranking activity). Draw-and-tell activity.
Interview Two with Parent(s):	NA.

Table Three: The additional tools used in each interview

Given the array, and variety of tools available, these five tools were chosen after much reflection and consideration (Punch, 2002). All the tools had been developed and used in similar research contexts and participant demographics previously, demonstrating a validity and applicability to this study (Punch, 2007; Thomas and O’Kane, 1998; Jenkins, 2015). The ability to personalise these tools to the study and to each child participant was also greatly appealing to me. For example, I adapted a ranking activity to produce the magnetic families and friend’s activity which allowed each child to personalise the magnetic board to represent their own families and friends as

opposed to using a preformed model representing 'a family'. An additional benefit of these tools was their flexibility in implementation without compromising the rigour and validity of their use. All the tools could be adapted depending on the needs and capabilities of each child (O'Kane, 2008). For example, the vignettes could be read aloud or the child could read them aloud/silently as they wished and the spider diagram could be used to draw or write on. Finally, each tool offered something different, reducing the reliance on a particular skill or interest of the child. On reflection, I felt these additional tools were useful, with some children finding them more valuable than others. In particular, I found these research tools gave me, as a researcher, the confidence and further support to communicate with children regarding their epilepsy. Specific reflections on each of the additional tools are discussed as they are described in more depth in the data collection section (5) below.

On further considering how to engage children with the interview process, I opted to use two semi-structured interviews rather than one. Given the complexity, and potential challenging, discussions I hoped to have with children and their parents I felt that trying to have one, longer interview would be too burdensome and potentially draining on children and parents. The addition of a second interview also allowed for follow up questions from the first interview to be raised and for the clinic appointment observation to be discussed in more depth. On reflection, I feel that the second interview allowed for a greater relationship to develop between the children/parents and myself, improving the quality of discussions and allowed the space and time for more in-depth conversation. The second interview also 'took the pressure off' the first interview and an anxiety to 'capture everything' straightaway as well as allowing for insightful discussions regarding the clinic appointment.

2.3 Research Design - Capturing Multiple Perspectives

While recognising the wealth of insight that children can provide on their own lives, the focus in this research was on the child as a distinct entity (James et al, 1998; Punch, 2003). In much of the initial research on the sociology of childhood, child-centred contexts were the main focus, concentrating on children's worlds in relation to other children, with the significance of adult-child relations including parents and healthcare professionals often neglected (Alanen and Mayall, 2001; Punch, 2003; Wyness, 2015). Intergenerational accounts can provide a more embedded picture of

children's lives, enabling researchers to compare and contrast the views of different family members, and build an understanding of family practices around illness (Harden et al, 2010; Zartler, 2010).

For this study, obtaining children's and parents' multiple accounts enabled exploration and rich understanding of the care practices and involvements in epilepsy-related treatment and management, as well as capturing the contexts this occurred within. It was felt that including parents would offer a complementary account and insight into child-adult relations and how children are involved in their care. The parent interviews were thus structured to obtain insights into how they perceived their child's involvement in care practices, whilst acknowledging their personal experiences of having and caring for a child with epilepsy though this was not a primary aim of the study. Insights from siblings and extended family members were additionally considered, but I concluded that this would produce a research project that would be too immense, given the time and resource constraints of a PhD. It is, however, an area worthy of further exploration (see e.g. Webster, 2017).

Despite the benefit of multiple perspectives, very little attention has been paid to how incorporating multiple accounts in research can influence the whole research process, with many studies overlooking the challenges of obtaining, managing and analysing multiple perspectives and the complexity taken for granted (Zartler, 2010; Harden et al, 2010). These challenges are identified and addressed as I discuss each of the stages of the research process below. Broadly, however, to ensure each perspective (child and parent) was heard, individual interviews were used.

2.5 Observational Research

An additional aspect of the study involved observing a routine epilepsy clinic appointment. Participant observation allows researchers to capture context and processes, providing insight into interactions between dyads and groups, as well as offering a view of the situation (Mulhall, 2003). A completely, full, picture of an observation is never completely possible (Delamont, 2004). Yet, observing children, parents, and their healthcare professional in a consultant appointment can offer detailed information and insights about the involvement and participation of children and how this is facilitated (or not) by parents and healthcare professionals. This

awareness would not necessarily have emerged from interviews alone, given the subtleties of involvement (Delamont, 2004). This perspective creates a third account alongside children's and parent's own perspectives of the clinic appointment. By combining observation of the clinic with interviews, a deeper, more detailed understanding can develop, from both the direct observations themselves and from the additional questions and probes developed from my own observations which I could ask during the second interview to gain more nuanced insights.

Again, my position as a researcher can influence the collection and interpretation of this observed data generation. In particular, the data gathered from observing the clinic appointments are the product of the inter-subjective processes between myself and what I am witness to (McNaughton et al, 2014). The insights I gained through the observations nevertheless provided familiarisation and understanding of how the clinic appointments happened and the interactions that took place.

In this section, I have detailed the theoretical underpinnings of the study and how these foundations have influenced the design of the study itself. Attention will now turn to the ethical considerations that concerned the study and the approval processes that took place for the study to be carried out.

3. Ethical Considerations and Approvals

Before exploring how data was collected, the ethical considerations and approvals required for the study, will be examined. The ethics of research have been the subject of extensive discussion throughout the methodological literature (Skelton, 2008; Gallagher, 2009). Ethical considerations are particularly pertinent and intensive in research involving children. As discussed previously, children are still viewed as a 'vulnerable' group requiring considerable protection, and even more so when researching an aspect of their health or illness (Mayall, 2001; Carnevale et al, 2015). In their review of NHS ethical committee opinions of research involving children, Angell and colleagues (2010) found that nearly three quarters of responses from committees tended to focus on children's status as 'vulnerable'. With this perception governing research involving children in healthcare settings and contexts, it reinforces a protectionist stance towards children (Powell et al, 2012). Angell and colleagues (2010) suggest that applicants for NHS ethical approval might increase their chances

of achieving a favourable outcome by being explicit about how they will handle children's vulnerabilities. This section will thus explore the ethical considerations associated with this study, alongside my reflections and management of them. I will focus on informed consent, protection from harm, and confidentiality and anonymity. A brief reflexive account of the ethical approvals required for my research will also be detailed.

This study was designed and managed in accordance with the University of Edinburgh's ethical research framework and NHS Scotland ethical principles, as well as following guidelines set forth by the British Sociological Association (2017). Additional ethical guidance was informed by the extensive literatures on research with children and families in the home and clinical settings (Smith et al, 2000; Alderson and Morrow, 2004; Jordan, 2006; Gabb, 2010; Lomax, 2012). Furthermore, although ethical approvals were required to begin the study and consequently demonstrate an initial ethical review during the planning of the research, I adopted an expansive, reflective understanding of ethical practice through ongoing consideration of the ethical dimensions of my work throughout the research process (Gallagher, 2008).

3.1 Informed Consent or Assent

Gaining informed consent is often seen as the gold standard of ethical research and practice, but it is not without criticism (Wiles et al, 2008). The core element of informed consent rests, firstly, on the participant being provided full information regarding the study they are being invited to participate in and, secondly, that the participant fully understands their involvement and the expectations required of them (Wiles et al, 2008). Irrespective of whether 'fully' informed consent is ever possible (Brosnan et al, 2013), this issue is particularly complex in research involving children.

Parents often play an active role in engaging their children in research, not only as 'gatekeepers' and consent-givers, but also as 'brokers' of their children's consent (Lewis, 2009). Yet, parents and children may hold quite different views about taking part in research and parents may be involved in persuading, or even coercing, children to participate (Lewis, 2009; Singh, 2010). This can cause tensions with conceptualising children as agentic subjects capable of giving consent when parents' perceptions are

that they are the responsible, ultimate decision-makers, not their child (Bushin, 2007; Lewis, 2009).

Reflecting on the legal dimensions of informed consent, the Age of Legal Capacity (Scotland) Act 1991 states that "a person under the age of 16 years shall have legal capacity to consent on his own behalf to any surgical, medical or dental procedure or treatment where, in the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or treatment". The Act clearly states that an assessment of competence must be undertaken prior to consent being attained, yet there are no attempts to explore (or explain) what competence means in this regard (Lewis, 2009). Generally, competency is taken to refer to a child's age and maturity, with adults determining that assessment (Alderson and Morrow, 2004). In the context of research, however, the Act does not set out any requirements or expectations regarding children's consent for research purposes. With limited, definitive, legal instruction, researchers may defer the decision to participate to parents (on behalf of their child) and only requiring the child to verbally agree after this (Hein et al, 2015). Thus, the consent process is underpinned by the inherent discord between researchers viewing children as capable social actors and ethical protocols designed to protect such a 'vulnerable group' by ensuring a thorough consent procedure (Gallagher, 2009).

The solution for many researchers and connected ethical guidelines has been the concept of assent (Dockett et al, 2013). Assent refers to a proxy consenting procedure where a parent, for example, provides informed consent of participation on behalf of a child, fulfilling an alternative informed consent procedure, with the child then verbally agreeing to take part afterwards (Cocks, 2007; Dockett et al, 2013). This process is often used where children are deemed to lack competency and parental consent is obtained instead (Alderson and Morrow, 2004). Such an approach to consent have been viewed by some scholars as disempowering for children, and as a failure to adequately take account of children's differing capabilities and levels of understanding (Bray, 2007). For this study, I used a combined consent and assent approach.

This combined style was primarily due to the recruitment approach I adopted. Before detailed discussions regarding my study began, parents gave their implicit consent

for me to talk to their child (and themselves) about participating by providing me with contact information. This initial implicit consent registered parents' interest in themselves and their child participating in the study. This meant that if a parent was not interested in participating, their child was de facto not asked if they were interested – reflecting little choice or decision-making power for children. Where parents were interested, children were considered to be 'assenting' if they were also interested in participating. However, in following British Sociological Association guidelines (2017), and my attempts to respect children's agency by providing a genuine choice of participating (or not), I also sought written informed consent directly from the child. Although, as parents had already agreed to hear more about the study, such written consent could also be considered a form of assent (Wiles et al, 2008). Due to the nature of the study, both child and parent had to agree to participate and provide consent.

To ensure that all consent obtained was informed I took a two-step approach: firstly, I provided suitable written documentation about the study and, secondly, carried out a dedicated discussion on what participating in the study would involve. Providing that the research study information can be presented in an easy to understand and age-appropriate manner, there should be minimal issues with allowing children to provide informed consent (Neill, 2005). In making such provisions, it privileges children's own ability to consent rather than their parents. The children's information sheets and consent forms I produced were designed to be clear and understandable, providing a wealth of information on the study, what would happen, and what they would be expected to do. Both documents were piloted with the Scottish Children's Medical Research Network's Youth Group and five children who I spoke to during informal conversations, and the feedback provided was incorporated in to the final documentation. Feedback included: removing some of the clipart on the paperwork as it made it look childish rather than child-friendly; reword some sentences to clarify meaning; and, illustrate the research process as a flow chart to provide a visual representation instead of purely text.

Before any consent forms were formally completed, I also had an in-depth conversation with children and parents regarding the study and what 'consent' would mean to both. These conversations involved showing children, and parents, the additional tools, the dictaphone used to record the interviews, as well as telling them

the questions that I might ask (e.g. what's it like to have epilepsy, to take medication, play outside with friends etc.). This process ensured that children, and parents, were well informed of the study and that children themselves were engaged with the process of consent, something that could be rather alien to children (Gallagher, 2009).

Moreover, the conversation attempted to reduce the social norms, peer pressure, and relations of power that can become embedded in the consent process when children are involved (Corrigan, 2003; Gallagher, 2008). As discussed above, parents can (unintentionally) present research as something that children cannot say no to participating in, coercing their involvement (Nilsen and Rogers, 2005; Lewis, 2009). During these discussions, and across the entire consent process, I was particularly sensitive to such implicit coercion (Singh, 2010). By carrying out such conversations I also attempted to mitigate any potential assumptions and uncertainties that either I, as researcher, or my participants brought to the study regarding participation and outcomes to the study and answered any questions before asking for consent (Pickersgill, 2011). Furthermore, the process of discussing the study made me, as researcher, confident that each child had developed an informed understanding of the expectations of them in agreeing to participate. In other words, I was assured that each child agreeing to participate, did so competently.

At this initial discussion stage, one parent chose not to participate and did not wish for her child to either: the mother had concerns about her son participating due to his mental health and current struggles with his epilepsy diagnosis. In this situation, the child had a complex medical history that, had I known of it, would have excluded them from initial contact and would not have sort either of their involvement in the study. The situation, also however, served as an important ethnographic moment in making clear the power parents have as gatekeepers to children's participation in research, as well as the difficulty of relying on others to make initial contact for recruitment. In all, though, I felt these consent discussions worked well and gave children the feeling of control over the process when they realised that they could (genuinely) say no to participating without any repercussions.

Despite this rather complex consent process, a condition of obtaining ethical approval from NHS REC stipulated that I create a parent's consent form which would allow their child to participate. This parental consent was to be used in situations where a child

was deemed to lack the capacity to consent for themselves. The form was mandated despite my own insistence that if I did not feel a child would be able to consent to the study themselves, I would not involve them (as I felt it would be unethical and unfair to do so). Given this, the form created was never used. I did not feel that any of the children approached would have any issues providing their own informed consent. This may not, however, be true for all children with epilepsy, given the extent of co-morbid conditions associated with epilepsy.

The concept of consent, however, cannot be viewed as a discrete event; rather, it must involve a continual dialogue between research and participant(s) (Alderson, 2007). After the consent forms were signed, and prior to the start of each interview and observation, children and parents were asked verbally again if they remained happy to continue. Similarly, within the interviews with children, and to address the potential power differential between myself (an adult) and them, I provided moveable thumbs. These thumbs were always placed next to a child, with the instruction that if I asked a question they did not wish to answer or if they were feeling uncomfortable they could indicate this to me either by simply saying or by turning the thumb downwards. This tool will be discussed more in the next section, whilst discussing protection from harm and distress.

3.2 Protection from Undue Harm and Distress

A further core ethical concern regards a researcher's duty to protect participants from undue harm and distress (British Sociological Association, 2017), such as when discussing sensitive topics in interviews. As this study explored experiences of the care, treatment, and management of epilepsy, I immediately recognised that some respondents could become distressed. Accordingly, several measures were put in place. First, and connected to the informed consent procedure, the in-depth conversation prior to consent being issued included a discussion of the interview topics. This ensured that most aspects of the interview were anticipated by the respondents, and they were reassured that there were no wrong answers or obligation to address all the questions. Second, as noted, moveable thumbs were provided to children. These provided another way to direct my attention to any discomfort. All of the children were able to 'practise' this during the initial consent conversation, much to their own enjoyment. Some extended this to the interview as Mike, a child

participant, added, after turning his thumb down during the opening three minutes of his first interview, "*oh wow, it works!*" as I changed the conversation from his school work to the latest children's movie blockbuster that I had seen.

Finally, I remained alert throughout all the interviews and observations for any (non-)verbal indications that a participant was uncomfortable or becoming distressed. The conversation was then steered accordingly. For example, Abby became distracted and seemed to withdraw slightly when talking about school and friends during her first interview; as soon as she began fiddling with her 'thumb', I changed the conversation. When I returned to the topic of school, using a different approach, Abby turned the thumb down again. At this point, I stopped recording the interview and stated that I would not talk about school again and let her know which remaining topics I would be asking questions. I then asked Abby if she would be willing to continue, confirming that she did not have to if she preferred not to. Similarly, Keira briefly mentioned that epilepsy surgery was being discussed as a treatment option for her but that talking about it always made her cry; accordingly, I took the decision not to ask too many questions about that beyond that initial probe about how it made her feel.

After each interview, I ensured that the respondents were fine with what had been discussed and asked if they had any questions or concerns. Where issues did emerge, either after or during the interviews, I signposted to relevant resources or support (e.g. contact information for ESNs and websites with further information). In all, I felt that I had conducted the research in a sensitive and respectful manner, and with due regard to children and parents.

3.3 Confidentiality and Anonymity

An additional and fundamental ethical consideration reflects the issue of confidentiality. This is underpinned by the principle of respect for autonomy (Wiles et al, 2008). In a research context, confidentiality should be taken to mean that any data collected during the process of research would not be disclosed without respondent permission, and presented in ways that ensure no individual could be identified (British Sociological Association, 2017; Wiles et al, 2008). Confidentiality was chiefly operationalised in my research through the process of anonymisation of the children, parents and healthcare professionals (Wiles et al, 2008).

However, confidentiality, and by association anonymity, remain difficult to guarantee in certain circumstances. This can be especially linked with concerns of child protection and the protection of vulnerable groups, which underlies most ethical discourses surrounding children and vulnerable adults (Hill, 2005). In order to balance the legal need for child protection procedures and confidentiality, it was decided that complete and unequivocal confidentiality could not be assured in this study. All children and parents, though, were reassured that everything discussed in the interviews would be kept a secret or private (i.e. confidential) where possible. The caveat to the confidentiality was made clear: if I, as a researcher, felt there was reason for concern (e.g. a child or family member were being harmed, medication was not being adhered to) I would be required to 'break' confidentiality. In these circumstances, children and parents would have, where possible, been informed of the need to disclose the 'private' discussion with others (e.g. healthcare professional, social services). This did not happen during any stage of the study.

To maintain participant anonymity, all identifiable features (e.g. names, locations) were removed from transcripts and pseudonyms used. This further ensured that the data could not be linked back to a specific participant or family. Children were also all provided the opportunity to create their own code names as a way to anonymise and link their data (Morrow, 1999). This proved to be great fun for children. Originally, I intended to use the code names throughout the analysis and reporting of the data. However, unexpectedly, most children told their parents their code names. I therefore generated new pseudonyms to ensure anonymity.

3.4 Ethical Approval

This study was scrutinised by the NHS Lothian Research Ethics Committee (REC) and NHS Governance Department (Research and Development). Applying for NHS ethical approval and governance is often deemed a complex, lengthy process (McDonach et al., 2009) that represents a burdensome 'hurdle' to be navigated (Brown and Agius, 2012). Despite the vast and daunting paperwork, the process of applying and obtaining NHS research ethics approval was gratifying. I was forced to articulate with great clarity and conviction exactly what I wanted to do in the study, account for a wide range of situations that could possibly arise, and ultimately to justify the need for the study to occur. Local approvals from the University of Edinburgh Centre for

Population Health Sciences Ethics Committee were not required, as the Committee deemed the NHS ethical process sufficiently rigorous. A summary application was submitted, however, for university record-keeping. The paperwork submitted to the NHS REC was attached as supporting documents to ensure greater clarity and transparency of the study to the university.

Comments from the REC on the application ranged from concerns over my response to a participant having a seizure during an interview, the meanings of informed consent versus assent, and clarifications over long-term data storage. Various aspects of my protocol were subsequently altered to meet REC requirements. A favourable opinion was granted by the REC in June 2014. A later amendment was submitted in December 2014 to extend the age range of child participants to 16 years, due to recruitment concerns (as will be discussed in section 4). Yearly reviews of the study have been submitted to the REC, including updates on progress with recruitment, data collection, and analysis. NHS Research and Developmental approval was also obtained.

4. Participants: Sample, Demographics, and Attrition

In this section, I describe the children and parents involved in the study, including the sample criteria, how they were recruited into the study, and their demographics. I also put forward critical reflections about the final sample and their recruitment.

4.1 Sample

The nature of qualitative research means sample sizes are often small in comparison to quantitative studies (Ritchie, Lewis, and Elam, 2003). Sample sizes in qualitative research are a point of disagreement, with the question of 'how many is enough?' asked during many research studies (Ritchie, Lewis, and Elam, 2003; Guest et al, 2006). In attempting to provide some clarity on this matter, Baker and Edwards (2012) asked fourteen qualitative methodologists their views on how many participants or cases were enough to sample for a qualitative study. Unsurprisingly, there was no consensus on the exact number required; instead the answer provided was always prefaced by 'it depends' (Baker and Edwards, 2012). In particular, it depended on the epistemological and methodological questions regarding the nature and purpose of the research, as well as the practical issues surrounding the researchers experience

and time available (Baker and Edwards, 2012; see also Green and Thorogood, 2009). The notion of data saturation has been frequently cited, in connection with the question of sample size, with many stating that sampling should be large enough to allow for a range of issues and themes to be identified and explored (Ritchie, Lewis, and Elam, 2003; Green and Thorogood, 2009).

For my research, a sample size of 25 was originally proposed. This was considered achievable, while having the potential to generate rich data. It was also congruent with the sample sizes of similar research (Silverman, 2011). Throughout the data collection I regularly reviewed recruitment and the sample size, and the level of data being generated. After ten months of recruiting and interviewing 23 participant families, I felt that the sample had provided a wealth of data. Many of the themes emerging were repeated across several interviews; given this, and due to the time constraints of the PhD cycle, I made the decision to stop recruiting.

The sample was purposively recruited using a detailed inclusion and associated exclusion criteria. The inclusion criteria for the study were:

- Child with active epilepsy aged 7 to 16 years.
- English is their first or primary language.
- Child must have been diagnosed with epilepsy at least one year previously.

A child with active epilepsy is defined as a child who has had at least one epileptic seizure in the last year or who is currently taking anti-epileptic medication (Meyer et al, 2010). It was felt that active epilepsy would cover a range of different types of epilepsy as well as whether the epilepsy was 'controlled' or 'uncontrolled'. Controlled epilepsy was regarded as epilepsy in which there were a limited number of breakthrough seizures either through use of AEDs, diet, or other therapies. Conversely, uncontrolled epilepsy was when seizures were more regular and not controlled. Children were also required to have been diagnosed with epilepsy at least one year previously. I felt that this would ensure that the initial diagnosis period would have passed and allowed treatment and management regimes to become familiar with children and parents.

The age range of 7 to 16 years was selected as few studies regarding chronic illness have included children between those ages, with even fewer obtaining children's own self-reports and accounts (Sherifali and Pinelli, 2007). Originally, the age range of those to be included was 7 to 11 years, with the aim of focusing on 'middle childhood' (Wyness, 2013). However, slow initial recruitment sparked a need to increase the age range to include those up to age of 16 years to boost recruitment. The demographics of the final sample are discussed below.

The associated exclusion criteria for the study were:

- If the child has febrile seizures or provoked seizures only.
- If the child has an unconfirmed diagnosis of epilepsy or diagnosed under 1 year ago.
- If the child has had a formal, or are waiting for, a psychological assessment and deemed to have an IQ lower than 70 (+/- 2 Standard Deviations).

The decision to exclude children with learning or cognitive difficulties (assessed by having a lower IQ) was primarily driven by the small nature of the study, my personal inexperience of carrying out research with children with considerable learning difficulties, and the concern it could significantly shift the research aims and focus of the research. Nevertheless, excluding children with a low IQ would have prohibited a significant population of children with epilepsy from participating in the research. A diagnosis of epilepsy is highly correlated with low IQ, associated learning difficulties, and conditions relating to the autistic spectrums (Appleton and Marson, 2009). In the context of this doctoral research, however, it was felt that this population would be served best by a separate study designed to capture their experiences of epilepsy and its treatment and management.

In terms of parent(s) involvement in the study, I advertised that the primary care-provider(s) would also be included as interviewees in the study. In situations of two parent-headed households, it was left to the parent(s) or carer(s) to decide who would participate in an interview. In some cases, both parents wished to be interviewed. Commonly, the interviewee was a mother on her own. This fits with other family-based research, where attaining fathers' perspectives has proved challenging (Ribbens-

McCarthy et al, 2003; Harden et al, 2010). I was, however, eager to include fathers' perspectives, so where possible facilitated their involvement (e.g. scheduling the interview that suited all work commitments).

4.2 Recruitment

Recruitment took place through the paediatric neurology clinical teams at two main regional hospitals in Scotland: an urban and a rural location. The clinical teams of both hospitals were given detailed information about the study, including the inclusion/exclusion criteria, and a suggested script on how to introduce the study to potential participants. For the urban location, I was able to attend an epilepsy clinic run for children in the area, which enabled me to be introduced to potential participants immediately. I was able to provide more detailed information to the child and their parent(s), as well as gathering contact information to follow up with them. This strategy worked well, with many families happy to be contacted again about the study. A small number of parents did not wish to leave contact information but did take further information. In the rural location, an ESN reached out to all the children's parents in the Health Board area that met the inclusion/exclusion criteria, asking if they would like to participate in the study, and if so whether they would consent to having their details passed to me. I then contacted them with more information, before following up with them again about their involvement.

It is unclear exactly how many children and parents were given verbal information about the study by either of the clinical teams but then chose not to receive further information or be contacted by myself. Some reasons (provided to either myself or the introducing clinical gatekeeper) for not wishing to take part included: being too busy, uninterested, not having anything to say, and not feeling that their child was capable enough to be involved. These responses all came from parents. To address this feedback, I altered the scripts provided to the clinical gatekeepers to offer more clarity.

In total, 29 children and their parent(s) opted-in to the study during this initial meeting by completing an opt-in form and providing their contact information. After a cooling-off period of two working days after initial meeting, contact was re-established. At this point, a time was arranged to speak with the child and their

parent(s) to discuss consent. Three parents chose not to continue with the study at this point, again citing reasons of being too busy, and not feeling they had anything to add. Two other parents proved to be unreachable after the initial contact point despite three attempts to contact them. One further parent removed their child from the study as consent was being taken, this will be discussed more in section 4.4.

The other 23 children and their parents were happy to be involved in the study. The consent discussion then took place, after which written consent was obtained from the child and their parent. Of note, one parent and child were eager to take part in the study but frequently had to cancel the arranged time for the interview due to the child's uncontrolled seizure activity. This highlighted potential challenges in recruitment and data collection that can emerge whilst researching childhood epilepsy.

4.3 Sample Demographics

The final sample was comprised of 23 children with active epilepsy (12 female; 11 male), and 20 mothers and 11 fathers. The table below (four) provides information regarding the children, their medical presentation of epilepsy or seizures, age at diagnosis, and the number of current and previous anti-epileptic medications they are taking. It also details which parent(s) was also involved in the study.

Child (& their Parent(s) involved in the study)	Age (Gender)	SIMD (quintile /decile)	Age at Diagnosis	Type of Epilepsy or Seizures*	Number of Medications (current / previous)*
Wayne (Alf and Robyn)	10 (M)	1 / 2	2	Idiopathic generalised epilepsy (with myo-clonic jerks)	1 current (1 previous)
Yasmin (Ash)	10 (F)	2 / 3	5	Focal epilepsy symptomatic	1 current (1 previous and emergency medication)

Craig (Lee and Annie)	9 (M)	5 / 9	5	Idiopathic generalised epilepsy and focal idiopathic	1 current (1 previously)
Susanne (Jane)	11 (F)	2 / 3	6	Childhood absence epilepsy	1 current (3 previously)
David (Colleen)	10 (M)	5 / 10	7	Benign childhood epilepsy	1 current
Mike (Don and Wendy)	10 (M)	3 / 5	1	Frontal lobe epilepsy	1 current
Rosie (Sue and Jim)	8 (F)	3 / 5	1	Generalised idiopathic epilepsy (with tonic-clonic seizures)	1 current (2 previous)
Jack (Judy)	13 (M)	4 / 8	9	Idiopathic generalised epilepsy	1 current
Keira (Geoff)	13 (F)	4 / 8	4	Temporal lobe epilepsy (with focal seizures)	3 current (2 previous)
Phoebe (Charlotte)	9 (F)	4 / 7	6	Childhood absence epilepsy	2 current (4 previous)
Abby (Shirley)	11 (F)	4 / 8	8	Idiopathic generalised epilepsy (with absences)	2 current (1 previous)
Melanie (Cathy)	9 (F)	4 / 8	6	Focal seizures (with bilateral convulsive seizures)	1 current

Nicola (John and Shona)	8 (F)	2 / 4	6	Temporal lobe epilepsy (with focal seizures)	1 current (1 previous)
Esther (Eric and Verity)	11 (F)	5 / 10	6	Focal onset (with bilateral convulsive seizures and absence seizures)	1 current and emergency medication (2 previous)
Courtney (Monica)	14 (F)	1 / 1	4	Focal onset (with bilateral convulsive seizures and absence seizures)	1 current and emergency medication (2 previous)
Iain (Derek and Jean)	10 (M)	5 / 9	7	Idiopathic generalised epilepsy (with myoclonic jerks)	1 current (2 previous)
Lucas (Carrie)	8 (M)	4 / 7	6	Left sided focal seizures (leading to bilateral convulsive seizures)	1 current (1 previous)
Philip (Duncan and Ellen)	8 (M)	3 / 6	6	Childhood absence epilepsy	1 current (1 previous)
Lily (Christine)	10 (F)	2 / 3	7	Benign childhood epilepsy and focal seizures.	1 current
Alex (Marcus)	11 (M)	2 / 4	7	Childhood absence epilepsy	1 current
Peter (Katherine)	11 (M)	4 / 8	8	Idiopathic generalised epilepsy and childhood	1 current (2 previous, including

				absence epilepsy	emergency medication)
Emma (Julianne and Ryan)	11 (F)	2 / 3	6	Benign childhood epilepsy	1 current
Maisie (Sharon)	8 (F)	1 / 2	5	Childhood absence epilepsy	1 current (1 previous)

Table Four: A summary of children's demographic and relevant epilepsy medical history

*(*As defined by parents and through the child's clinical notes)*

As can be seen in the table, the children and parents were from a range of socio-economic backgrounds, as assessed by the Scottish Index of Multiple Deprivation (SIMD) quintiles, and refined by parent's occupations. Three children were from the least deprived quintile, six from the second least, three were mid-range, seven were from the second most affluent, and four were from the most affluent quintile (Scottish Government, 2016). Though it is understood that this measure of socio-economic status may not be accurate, it serves as a useful indication. There was minimal ethnic and national diversity in the sample recruited; only one child and parent involved were Indian-Scottish, with the rest identifying as White-Scottish or White-British.

Despite the dominance of medication as a treatment for childhood epilepsy in this study, as noted in the Introductory chapter (one), other treatment options exist which aim to prevent seizures. None of the children in the study used treatments other than medication, and there was little reference to alternatives by children or parents. Two children were in the process of being considered candidates for epilepsy surgery, but this was minimally mentioned by either parent. One child was unaware of this treatment option at the time of her interviews and the other child only referred to it as a potential treatment once. This thesis therefore discusses medication as the primary treatment option for epilepsy.

4.4 Attrition

The risk of attrition was high in this study, as data collection was over two time points and there was a possibility of epilepsy becoming uncontrolled or treatment changing. To reduce the likelihood of children and parents withdrawing after losing interest in

the study, and to thank them for participating, children and parents were told that they would receive a small, non-monetary, thank you gift (a High Street Shop Gift Voucher) at the end of the study. Small updates on the study's progress were also sent out to children and parents over the course of their involvement in the study and a summary of the main findings provided after the thesis was submitted.

However, due to unforeseen circumstances three children (and their parents) were purposively withdrawn from the study after the first child and parent interview. Consequentially, the observation of a routine clinic appointment and the second interviews did not go ahead. One child was removed due to the potential involvement of social services and additional health issues within the wider family. It was felt that the second interview and clinic observation would be too burdensome and intrusive into their life at that particular time. A second child was also removed due to them undergoing epilepsy surgery in between the two potential interview times. This change in treatment would result in very different data from the rest of the sample, as well as being demanding on the family at this stressful point in time. The third child and parent became unresponsive and it was felt that they did not wish to continue with the study. All three children and parents were still thanked for their involvement and told that the data collection phase of the study had to come to an end, as opposed to being told they were actively withdrawn. A thank you gift was sent in the post to all three.

In total, 23 children and 31 parent(s) were interviewed with the first interview; 20 children observed during a clinic appointment; and, 20 children and 28 parent(s) interviewed with the second interview. The following section describes and reflects critically on the data collection process through examining the research methods used (interviews, observations and additional tools) and their role in the generation of data.

5. Generating Data

Two interviews with children and their parent(s) formed the basis of the study, with an observation of a routine clinic appointment supplementing the second interview. Interview topic guides for the child and parent interviews were developed following the extensive literature reviews, and informal discussions with parents and children with epilepsy, and other experienced researchers. The topic guides were intended to

help direct the flow of the interview discussions, providing initial questions and follow up probes. The second interview was more fluid and centred around the observation of a routine epilepsy clinical appointment, with questions focused on what had happened during the appointment. In the child interviews, additional research tools were incorporated (discussed fully below). Children and parents were, where possible, interviewed on the same day.

Given that my role as a researcher and the nature of the relationship I developed with the children and parents would influence the data generated, I attempted to mitigate this (Punch, 2002; Gallagher, 2009). Researchers can be viewed as 'an unusual adult' (Christensen, 2004), so how I was perceived was important. In introducing myself to the children, I went by first name abbreviated – Becky ('as only my Mum calls me Rebecca'), differentiating myself from a teacher or a doctor that would be referred to by their title and surname. Connected to this, I explained who I was – a researcher ('someone interested in finding out more about things') - and importantly what I was not, i.e. a doctor, nurse, or teacher. Further, as a mark of respect, I willingly disclosed information about myself and allowed any questions children or parents wanted to ask. Children rarely asked questions initially but did so after the interview. Such questions included: had I ever seen a brain ('not really, but I have seen pictures like MRIs of brains'); what was my favourite colour ('yellow'); and whether I had ever had a seizure ('no, which is why I want to know a lot more about it from smart people who have').

When discussing what participating in the study meant, I explained it through the request for help; i.e., I needed their (children and parents) help to find out more about childhood epilepsy and what it is like to have it and manage its treatment. Phrasing the study aims in such a way placed children (and parents) in the role of expert and the researcher in a non-expert role, encouraging their own opinions and views to be expressed (Smith et al, 2000). I felt this approach was useful and encouraged children to see that their contributions during the interview would be welcomed and helpful. Philip commented during this discussion that he was a good helper and would help me the best he could and Rosie took great pleasure in telling her Dad (not initially present) that she was helping me a lot because she was smarter. These strategies, I felt, served to create my identity and role as researcher as somewhat unusual but also engaging and ready to listen.

After the introduction, and after ensuring all questions and concerns were answered fully and written informed consent was obtained from children and parents, I began the interviews. The first interview generally happened on a different day after the written consent had been granted (usually a couple of days later). On four occasions, this was not possible. Children were offered the opportunity to go either first or after their parent(s) interview; all but three children chose to go first.

Children were also given the choice and told that it was their decision as to whether their parents were allowed to sit and listen to the interview. This question was always asked in front of parents, to make clear that it was the child's decision rather than mine. The presence of parents during interviews can stifle children's contributions with interruptions, prompts to certain responses, or by offering their own interpretations of their child's views and feelings (Spratling et al, 2012). However, children may feel more comfortable with a parent present, and parents may wish to be in the room (Irwin and Johnson, 2005). The majority of children were happy to 'kick their parent out' (as one child put it) of the room and to conduct the interview one on one. The decision to choose was welcomed by the children. No parent actively objected to not being allowed to sit in on an interview where a child chose to be alone, but I did ensure that the door to the room we were in was always open to reassure parents. During five of the children's interviews with parents excluded from the room, the child's parent found a reason to enter the room after the interview began – for example, bringing in drinks and biscuits, putting a book on a bookcase. I regarded these slight interruptions as 'check-ins' by parents to ensure all was fine; they were anticipated and rarely disturbed the interview flow.

Parents were also offered the choice as to whether they wanted their child to sit in on their interview or if they would rather they left the room. Most parents requested that their child leave the room. This was met with some resistance by a few children. To mitigate it, I politely reminded the children that they had been given the choice and it was only fair that their parent also was given the same choice. Joint interviews were offered to parents' if more than one parent wished to participate however to reduce the burden of participation (MacLean and Harden, 2012).

The next three subsections will explain the three data generation points (interview one, the observation, and interview two) and detail my reflections on them. To note,

to ensure rigour and validity across all interviews and observation I followed the same semi-structured interview guides (appendix 2) with each participant.

5.1 Interview One

The first (semi-structured) interview was conducted in (what was assumed to be) the comfortable and familiar setting of the family home (Gabb, 2010). This setting was employed to increase the likelihood that children would feel relaxed, facilitating their involvement without the need for parents being present (Irwin and Johnson, 2005). The first child interview was designed with the aim of exploring children's experiences of epilepsy in terms of their home and school life. Accordingly, I probed around treatment and management, seizure activity and recovery, friends and family, and their thoughts and feelings about epilepsy more generally. To facilitate these discussions, I made use of additional tools: spider diagrams, magnetic families and friends, and comic book vignettes. Tool use was not regarded as data per se; rather, the tools were intended to facilitate children's engagement with the interview and their verbal contributions.

Spider diagrams provide a means to 'brainstorm' and discuss thoughts, feelings, and understandings of a particular topic that reach out of the 'spiders' legs (Punch, 2007; Johnston, 2008; Johnson et al, 2012). In this study, children were given an A3 sheet of paper with the word 'epilepsy' written in a circle in the middle, and each child was asked to draw legs on to this central 'spider' with all their thoughts, experiences, and feelings about epilepsy. They could use words, sentences, drawings, or a range of emotion-faces stickers to annotate their diagram, as well as having a wide range of coloured pens. As children added legs to their diagrams, their additions provided a springboard for a more detailed discussion surrounding what they thought of epilepsy, exploring their thinking processes and reflections. After a while, and depending on what had already been added, I suggested legs to add to the diagram including, 'what does epilepsy mean?', 'how does it make you feel?', and 'what do family and friends think?'. These more directed probes assisted in steering the conversation.

I felt that a key benefit of the task was it enabled the children to settle in to the interview and begin thinking about epilepsy and their experiences of it in an open-

ended way. Additionally, it provided children time to think about what they wanted to include whilst not under pressure to respond immediately to a particular question. As with all of the additional tools, spider-diagrams were introduced to children in a flexible manner (Bushin, 2007), and their use was dependent on what the children preferred. Some children were at ease and confident with straightforward talking whereas others preferred a task-based activity. Eight children did not use the spider-diagram at all: these children were confident in discussing their lives and experiences of epilepsy without the need for such prompts.

For the other children, the spider-diagram proved useful for encouraging discussion when they felt "*I don't really know the words to tell it*" (as Maisie explained to me whilst drawing a picture). Similarly, for these children it offered a form of distraction to the interview and something they could do whilst talking to me. For example, Keira appeared to be uncomfortable regarding some of the questions I asked, particularly around her seizures; having the paper and colouring-in crayons nearby allowed her to doodle during these questions whilst contemplating her answers. Whilst children said and either drew or wrote on their diagrams, I also began doodling on my own piece of paper. By participating in the activity, I was able to slow the conversation down and talk about what we were doing instead of asking questions on epilepsy. This proved useful when I felt that children were finding the questions difficult. Similarly, it allowed any silences created by drawing or writing to be less tense or as if I was hurrying them to finish. My own doodles were frequently ridiculed by children due to my own inabilities with a crayon, with the result that the children relaxed further as we laughed together at my drawings. In reflection, the spider-diagram offered most of children the time and opportunity to express their thoughts and feelings of epilepsy in a different way that aligned with their own capabilities and interests.

To explore children's experiences of and involvement with the treatment and management of their epilepsy on an everyday basis, I introduced the magnetic families and friend's tool (Thomas and O'Kane, 1998). The tool encouraged children to think about their, and others, involvement in their everyday treatment and management of epilepsy. Children were given blank magnets, and asked to think of the people in their family who help look after them and either draw a picture of them or write each person's name on each magnet, including one for themselves. Once

complete, the magnets were placed on a board, where they could be slid around. Children were then asked questions about epilepsy and treatment regimens in relation to these family members; for instance, 'who is involved in their medication?'. The children could then rank the magnets along the sliding scale of most to least. The same questions were asked about teachers and friends at school (a fundamental aspect of children's lives outside the family home). Questions regarding epilepsy management at school were then asked in a similar fashion with children asked to rank the people they had magnets for on the sliding scale.

Although categorical data could have been gathered with this tool (akin to a Likert scale) it was deemed inappropriate and needlessly reductionist (Silverman, 2011). The process of getting children to consider who and how they and others (such as parents, siblings, and friends) are involved in their treatment and management of epilepsy were the key areas of interest: the tool merely offered an alternative and interesting way to engage children with these discussions. The position on the board was not as important as the reasoning underlying it and the discussions that were had around it. Moreover, the interactive and fluidity of moving the magnets offered something different for children to engage with and something that they (on the whole) seemed to enjoy. This seemed to be increased by their ability to customise (and then keep) their magnets.

The final tool I used during the first interview with children was also used in the first interview with parents: namely, comic book vignettes. Vignettes have been used by researchers from a wide range of disciplines to explore a range of social issues and problems (Barter and Renold, 2000; Bloor and Wood, 2006). As stories, vignettes provide concrete examples about individuals, situations, and structures that participants can offer their thoughts on (Braun and Clarke, 2013). The vignette provides enough context and information for participants to have an understanding of the scenario being depicted, whilst remaining vague in ways to compel participants to 'fill in' detail and to answer open ended questions about the story (Jenkins et al, 2010; Braun and Clarke, 2013). The benefit of using vignettes in researching childhood epilepsy has previously been highlighted; for example, Elliott and colleagues (2005) felt that although one-on-one interviews with children in their study on the impact of epilepsy on quality of life indicated some appreciation of the meaning epilepsy had in children's lives, the use of vignettes could have yielded more fully the meaning of

epilepsy in the lives of these children. Similarly, Jenkins and colleagues (2010) illustrated that research participants seek to make sense of vignette situations in ways that are not entirely distinct from how they may seek to make sense of everyday lived events. As such, an interviewee's response to a vignette may well carry some predictive power in respect of how they would behave if they were to be subsequently presented with a similar, 'real-life' event (Jenkins et al, 2010). Thus, vignettes can be a useful tool for exploring less 'acceptable' treatment and management strategies of epilepsy, such as refusing to take medications (Jenkins, 2015; Jenkins et al, 2010).

In my research, three vignettes were used to explore experiences of epilepsy and associated treatment and management regimes and decisions that could be typically associated to having and caring for a child with epilepsy. The topics of the vignettes included: Ben, a child, who does not like taking medication; Louise, a child, who decides when to go to bed (child's responsibility); and Victoria's Mum, a parent who does not let her child (Victoria) play outside with friends in case they have a seizure. The topics were developed based on observations of clinic appointments and from informal discussions with parents and children with epilepsy to ensure they were realistic. The vignettes were presented in the form of a comic strip to be more visually appealing and written in plain English to ensure easy comprehension by children and parents. Parents reflected enjoying reading them and were frequently interested to know how their child responded to them (which I refrained from doing, for reasons of confidentiality). Children particularly enjoyed them and they created some discussion on the different scenarios. I felt that more data could have been generated through their use, but they were deployed at the end of the interview when most children began to tire. In reflection, doing two shorter interviews for these topics would perhaps have been better, particularly for the younger children.

The first parent interview focused on exploring what having a child with epilepsy meant to them, and their experiences of treatment regimens and seizure management. Aside from the comic book vignettes, no additional tools were used within their interviews. The interviews were semi-structured with opening topic questions and a range of connected probes. They typically lasted longer than those of the child (on average, 55 minutes). The joint or couple interviews with both parents went well; where one parent spoke more than the other, I 'checked in' with the quieter parent for their input in order to ensure throughout the interview that both parents

had an opportunity to participate. Through the couple interviews in particular, rich data in terms of their thoughts and feelings of epilepsy and particularly their management, transpired. The parents often spoke about the different aspects together, sharing their experiences and insight with very little probing and additional questions.

Both the child and parent interviews (one and two) were audio recorded and transcribed fully. The transcripts also included notes about demeanour, interruptions, and any silences that occurred to ensure a more rounded account of the interviews. Any questions that arose as I transcribed were also noted in a separate file to ask in the second interview. It was during the transcription that the data was anonymised.

What surprised me by the first interviews was the huge sense of welcome and willingness by all the children and parents to be involved in the study and share their stories and experiences. Although initially it took a little bit of encouragement with the children, they all provided thought-provoking insights and conversations. I do not think that I anticipated the lack of other opportunities children would have had to talk about their epilepsy with others, which meant that my questions would have come across as more challenging than I first considered. After my first five interviews, I ensured we spoke about 'ice-breaker' topics for longer, connecting the insights from these conversations with the questions about epilepsy to make them seem less direct. The additional tools were particularly useful in this regard. The emotion behind many of the parents (and some children's) accounts, reflections and discussions and the general emotional toll of travelling and interviewing a number of participants in quick succession was also somewhat unexpected.

5.2 Observations of Routine Clinic Appointments

The observation of the routine epilepsy clinic appointment offered my second point of data generation. By observing children, parents, and the healthcare professionals in this setting, I was able to develop a better comprehension about the involvement of children, how this was or was not facilitated by parents and healthcare professionals, and how decisions about the child's epilepsy treatment and management are taken. This awareness could not have been obtained through

interviews alone (Delamont, 2004). Moreover, by combining observation in the clinic with interviews, a deeper understanding and additional themes emerged.

The clinic appointments formed a standard part of paediatric epilepsy care in South-East Scotland. They serve as 'check-ups' to ensure treatment regimes are working effectively and provide the opportunity for children and parents to discuss any issues or concerns they have regarding the protocols, and epilepsy more generally. The appointments were usually led by paediatric neurology consultants and ESNs (Epilepsy Specialist Nurses), and were held in various clinical facilities. Due to the geographical spread of the children and parents in the study, I visited three different clinic sites: a children's hospital, a district general hospital, and a small community hospital. I observed one such clinic appointment for twenty children (attrition of three since the first interview).

The observations began once I had met with the children and their parents in the waiting area of the hospital and had confirmed verbal consent to continue. I also took this moment to remind children and parents that during the appointment I was there to just watch, and that I would be making notes but that it was just to help me remember what happened so we could talk about it afterwards. During these 'waiting room' observations, I noted "the spaces, actors, activities, objects, acts, events, times, goals and feelings to which I am witness" (Spradley, 1980: pp.78). These were sometimes brief written notes, but mostly what O'Reilly (2008: pp.73) terms "head notes"; i.e., notes on where children sat, whether this was self-driven or directed and where this seat was in relation to others in the appointment.

Once the child was called in to their clinic appointment, I would follow children and parents in to the appointment and sit in a seat that was usually to the side, away from the family. This was to clarify my position as an observer of, rather than a participant in the appointment. I paid attention to the questions being put forward and to whom they were addressed, in addition to each individual position in relation to one another (e.g., whether they were facing each other, or the healthcare professional was at their desk). I also made notes of what happened, in what order, and for what reasons. These notes included as much information as possible, including the descriptive, such as "dates, times, details, and background information" (O'Reilly 2008: pp.73), as well as my impressions of what was happening (Carmack 2010). These notes often took the

form of shorthand I developed to track the discussions, and I made use of predefined headings: 'content' (what is being discussed), 'engagement' (levels of engagement), 'interactions' (how and between who), 'questioning' (how and between who), 'presentation' (how are questions/information being discussed), and 'other'. These headings allowed me to record as much detail as possible quickly and efficiently – though during some of the more comprehensive appointments this was slightly challenging. My notes were always written up and expanded upon the same day as the appointment to ensure that the observation was still fresh and rich in detail in my mind (O'Reilly, 2008). I also noted any questions that came to mind during the observations to follow up on during the second interviews.

The observations did not always run smoothly however. As the clinics frequently ran late, I was often asked whether I could enable a child to be seen more quickly or to 'hurry doctors up'. The questioning or perception of my influence placed me in an awkward position in this regard. Furthermore, many of the clinical teams recognised me and often acknowledged my presence which often worried me in how it could come across to the children and parents I sat with. Although on the whole, I feel that my presence did not hamper the flow or conversation of the appointments, an aspect that I was concerned about prior to commencing this stage of data collection.

5.3 Interview Two

The second interview usually took place in the hospital directly after the routine epilepsy clinic consultation that I observed. When this was unfeasible, the interviews were again conducted in the family home. In the clinic, a quiet office was used for the interview and both children and parents were made to feel as comfortable as possible in the space (including through the provision of drinks and snacks). As with the first interview, children and parents were asked if they wished the other to be in the room with them during their interview. All bar three children elected to have their parent sit with them for this second interview. This difference between interviews held at home and in an office space near the clinic, may illustrate the use of a different and unknown place for the interview on children's comfort levels.

The focus of the children's second interview was the observed clinic appointment, and their own and others' involvement in it. I asked children to reflect on the time before

the appointment, the time during, and what would normally happen afterwards. To aid the discussions, a ranking exercise - 'pots and beans' - was used as an additional tool. It was used to explore the clinic appointment and involvement regarding the conversations had, and decisions made, if any. Before introducing the task, children were asked to reflect on their preparation before and involvement within the appointment. They were then asked to draw or write, whichever they preferred, on a piece of paper who was in the room with them; for instance, themselves, a doctor, ESN, and parent. After this, they chose between different coloured pots to represent each of these individuals. Children were then asked to distribute the beads amongst the various pots from most to least in response to statements such as: speaking in appointments, asking questions and making decisions. They had to decide how many beads each pot deserved on a scale of most to least, and then asked to explain how they reached their decisions. For example, on reflecting that the doctor spoke the most, a child would put the 'most' number of beads in the 'doctor's' pot. The ranking exercise offered insights into how children viewed their and others', participation in clinic appointments and how this could be improved. As the beads were quite noisy when being poured into the pots and frequently bounced out and off the table, it created a sense of messiness and fun that the children enjoyed.

Such ranking exercises can be used to obtain quantifiable data that can be easily compared with other participants (O'Kane, 2008). However, as with the magnetic families and friend's tool, creating quantifiable data was deemed unnecessary and would not reveal any nuances to involvement. The exercise was instead used as an interactive tool to engage children in reflexive thought surrounding their own and others' involvement in clinic appointments (i.e., prioritising the discussion had around the tool, rather than the output of the tool itself). However, using the tool did lead children to discuss involvement in terms such as 'she spoke the most/he spoke the least', perhaps structuring how children phrased their thoughts of involvement. I feel as a tool it encouraged children to reflect and discuss their involvement, which could have proved rather nebulous to explore otherwise.

The second interview for parents followed a similar structure to that of children's, without the use of additional tools (to the disappointment of three parents). Discussion was focused on preparations before the clinic, discussions during the appointment, and afterwards. Additionally, parent's perceptions of their own and their

children's involvement during the appointment was of particular interest. Hence, questions were asked about what they considered their role to be in the appointment and how they viewed their child's involvement and contributions.

Across the majority of the interviews, the second interview was much more relaxed and flowed easier than the first. I think this was due to the familiarity I had with the participants and that they had with me. The links and questions afforded by the observation of the clinic appointment also assisted. I also felt that the decision to have two interviews was greatly appreciated as I had the opportunity to follow up any outstanding questions or clarifications from the first interview.

In total, data was collected from 102 (children and parent(s)) interviews and 20 observations. This provided a range of rich and interesting data to explore. The time and insights provided by children and parents was humbling and greatly appreciated. The boundaries of this written thesis sadly meant that not all of what emerged from these interactions could be included. Yet, each story and perspective remain with me and fed into the analysis and ultimately the creation of this thesis and associated future outputs.

6. Analysis: Strategy and Presentation

In much of the previous research on childhood epilepsy, there was often limited discussion of the analysis approach adopted (Harden et al, 2016). The findings from the studies are usually analysed on a very broad and surface level, with minimal attempts to integrate with theory or concept development (Moffat et al, 2009; Camfield, 2007; Kerr et al, 2011). Building upon this, when children have been included in a study with their parents' there is often limited effort made to integrate these perspectives or to contextualise them within the same family (Mason, 2002; James and Curtis, 2010). This can cause fragmentation and the pitch parents' and children's views as opposing, a core critique of numerous multiple-perspective research (Lewis, 2009). This section will detail the analysis strategy adopted for this research and how it has managed the differing perspectives attained.

My method of analysis used a Framework approach, which comprised a thematic analysis of the data in a substantive and cross-sectional manner (Spencer et al, 2014).

This approach supported a process of familiarisation of the data, summarisation, description, explanation, and leading towards an abstracted interpretation of the data. This approach ensures the analysis remains rooted in participants' contributions but moves towards an interpretation that connected and reflected themes emerging (Spencer et al, 2014). Each of these stages will now be explained in more detail as I discuss the process.

The analysis of the data never officially started as it was an on-going and intrinsic part of the whole research process (Spencer et al, 2014). As interviews were conducted, I remained aware of themes and points of discussion that were developing and fed them back in to the future interviews and kept records of my thinking to feed in to later stages of the analysis. As interviews were digitally-recorded, full transcripts were created. I explored the transcripts substantively to make myself familiar with the data and to produce data-driven descriptions and summaries. From reading, reviewing, and discussing the transcripts with my supervisors, I developed a coding framework and gradually refined it in order to index and analyse the data using NVivo. The task to analyse and represent my findings proved to be a significantly daunting part of the research process, given the volume and diversity of the data.

Practically, I had a wealth of data; with 122 discrete (interview and observational) data points to engage with. The process of reading and unpicking each was challenging and at time felt insurmountable. I spoke to many people during this stage, as I questioned my progress: for instance, was I reading too much in to the data, was I projecting on to the data? It was reassuring to hear that I was not alone in my anxiety, with suggestions made to keep a note of all these thoughts to ensure they are kept in check and a common reflection was made: 'doing analysis is like wading through mud'. This rang very true and something I held on to over the long and protracted year of analysis. During this year, I coded all the interview transcripts and observation notes in NVivo creating additional volumes of data. Themes that emerged from this intensive analytical process included: support, information needs, care roles and responsibilities, and understanding and discussing epilepsy.

From the coded NVivo files I created thematic charts on each of these themes. The charts detailed the sub-topic of each theme in the columns (e.g. understanding, with sub-topics epilepsy, medication and seizures) and descriptions of each individual

participant's responses to it in the rows (e.g. Rosie, Abby) (Spencer et al, 2014). The emphasis of thematic charts is on synthesis of the data (summarising without losing content or context) to map the range and diversity of each theme across and within participants. The charts produced were large and cumbersome, yet, I felt reassured that all the data had been considered and integrated systematically – nothing had slipped through (Spencer et al, 2014). It was during this time, I took three months out of the PhD programme to complete an internship. This time away gave me the breathing space required to have a fresh look at my data and analysis.

Reading in and across the charts and data summarises, I built explanatory accounts and kept copious notes. These accounts recorded linked ideas, patterns and contradictory thoughts that developed as the charts were explored (Spencer et al, 2014). As my ideas developed it led towards an abstracted interpretation of the data produced and illustrated in the thesis. Throughout each step of the Framework approach I continually referred back to data summaries I had created and the transcripts to ensure a process of verification as explanations and interpretations developed (Morse et al, 2002; Spencer et al, 2014). This ensured the attainment of rigor using strategies inherent within the qualitative and analytical approaches adopted (Morse et al, 2002). Further, in seeking to ensure 'trustworthiness' and rigor, findings were re-examined alongside the transcripts and notes I had made before and after each interview. These notes had been taken in attempts to capture the 'feeling' of the interview - something a dictaphone does not necessarily pick up. By carrying out these 'check-ins' it re-affirmed the credibility and trust of the analysis produced (Morse et al, 2002).

As my study made use of multiple-methods and intergenerational accounts, I was particularly mindful of the ways in which these aspects could influence my analysis. The use of multiple-methods can cause issues with regard to analysis due to the confusing picture that can arise from a number of disparate analyses. Examining all of the data gathered from the methods outlined above at once, in concert, enabled me to produce a more integrated analysis (Chamberlain et al, 2011) which retained a 'messiness' that more accurately reflected the realities of life (Chamberlain et al, 2011). Further, as noted, the data from the tasks carried out with the children was not directly analysed in terms of pictorial content (e.g. spider diagrams) or position of ranks (e.g. ranking activities). Despite not being included in the analysis, all of the documents

created were kept (either the original or a copy depending on whether the child wanted to keep the original). Keeping and referring back to these documents and the transcripts allowed me to almost recreate the interview. This added a different dimension to exploring themes and aspects of note.

With intergenerational perspectives present in the study any analytical strategy used must be reflexive to ensure that existing power relations and culturally based assumptions are clearly addressed and articulated (Harden et al, 2010). Ribbens McCarthy and colleagues (2003) reflected that research should aim to produce a 'story' of the differing perspectives, whilst recognising that family members will present different versions of it. This approach allows for an interpretation of the data that does not presuppose to represent the 'truth', but rather presents a series of potential interpretations (Ribbens McCarthy et al, 2003; Harden et al, 2010). By interlacing individual accounts it is possible to create a story of epilepsy and care as a whole, whilst still retaining individual, different perspectives which created the bigger story (Harden et al, 2010). In the context of this study, I independently explored the nuances of each individual perspective (child and parent), to capture the uniqueness of their experiences and accounts of epilepsy and associated treatment and management. Afterwards, I brought the individual accounts together as I explored the explanatory accounts and began to abstract the meanings, making notes on areas of discord and accord between the two generational perspectives. These notes were used to add further dimensions to the stages of the framework analysis. By maintaining initial distance between children and parents accounts it reflected the theoretical underpinning of the study created by sociology of childhood principles.

In reporting the results, just as with analysing the data and projecting the theoretical underpinning further, I attempted to balance all data points – children, parent, and observation – and sought to represent each perspective fairly. Children's data can be seen as more fractured and looser than comparative adult data, with more probes and questions required to generate the data; adults, on the other hand, were more able to provide longer, more detailed responses (Gillett-Swan, 2017). This has implications for the length and presentation of quotes. Children's quotes presented are often shorter or embedded around the questions I asked, compared with parents where longer quotes are set out. Thus, it is important not to connect length or quantity of quotes, with quality of data presented.

Additionally, connected to the concerns of anonymity, all participants were given pseudonyms. Similarly, to maintain the familial connections between children and their parents' data, I have presented their data with this connection, for example: 'Ash, Yasmin's Dad'. Although this presentation runs the risk of being wordy, I felt it was important to allow a picture emerge of each dyadic and the various agreements and disagreements.

7. Summary

This chapter has detailed the research design and methodological approach adopted for this study. To explore the research questions a qualitative design was used, drawing specifically on two semi-structured interviews with children and their parents, and an observation of a clinic appointment. The central issues of researching children's lives, generating multiple inter-generational perspectives and the management of such perspectives have been discussed and reflected upon ensuring their thorough consideration. A rigorous account of ethical concerns and processes were additionally provided, embedding the study in ethical practice.

The more practical aspects of the study were also provided. The data was drawn from the interviews with 23 children and 31 parents, observations of 20 children's routine clinic appointment, and second interviews with 20 children and 28 parents. The interviews with children were also aided by the use of additional research tools namely, spider diagrams, two different ranking activities (magnetic families and friends and 'pots and beans'), comic book vignettes (used with parents as well) and a draw-to-tell activity. Finally, my method of analysis - a framework approach comprised of a thematic analysis of the data - was explained alongside my reflective accounts of managing the volume and messiness of the data generated. The following three chapters detail and explore the data generated, drawing out key findings and interwoven themes from children and parents' accounts.

Chapter Four: Meanings and Understandings of Epilepsy

1. Introduction

To explore children's experiences of and involvement in their childhood epilepsy treatment and management, appreciating how it becomes understood, conceptualised and incorporated into their lives, is key. This chapter will examine how children understand their epilepsy, how this understanding is created and shaped, and what this can mean for children's impressions of their condition. In conjunction with this, parent's role and contributions in creating and maintaining these meanings and understandings children develop will be explored. Experiences of epilepsy can however vary depending on the type(s) of seizure and epilepsy diagnosed (Moffat et al, 2009). As detailed in chapter 1, children experiencing absence seizures will experience seizures differently to a child with myoclonic events for example. This chapter will thus explore how children in the study, who had a variety of epilepsy and seizure types, make sense of their epilepsy and how they experience it. This will contextualise childhood epilepsy in children's lives enabling an in-depth examination of their meanings and understandings of epilepsy. Furthermore, such discussion will assist in the exploration of how knowledge acquisition and understandings can influence children's agentic potential and their involvement in their treatment and management.

The chapter begins by exploring what children understand by 'epilepsy' and the knowledge they hold on the condition. The means by which others, including parents and healthcare professionals, influence how children learn and understand epilepsy will then be examined, alongside the nuances of what information is given and what is withheld. Within this parent's own understandings will be explored as a means to appreciate their own learning, conceptualisations, and meanings attributed to epilepsy. Next, how children's understandings are shaped by their experiences of epilepsy, namely seizures will be examined. The impressions these meanings and understandings create and how they influence children's view of the condition in the context of their lives and the implications this has in disclosing their condition to others will then be unpicked before summarising the findings of the chapter. The

findings will be connected to the wider literature and draw out overarching themes of agency and involvement.

2. Children's Knowledge and Understanding

What children knew and understood about epilepsy varied considerably. Only three children demonstrated knowledge of the condition that incorporated descriptions of the brain and its role in how seizures occurred (Fisher et al, 2017a). As Jack explained:

Basically, there is something in the brain stopping, erm some stopping erm some objectives getting to the right part of the brain so it erm it makes you act in different ways because it's not got part of its constructions.

Similarly, Peter added:

I know how a seizure can be caused, it's like I think you have a little bit of... little, little bit of electric things going through your brain and then sometimes they get hyper I think, like, and then that's what makes you have a fit.

Likewise, despite initially stating: "I've got absolutely no clue" Esther went on to explain, "When you're like... When... you've got electricity going through your brain and when the electricity goes all weird and funny you have a seizure". Esther's initial hesitancy might reflect a lack of confidence on her understanding and knowledge, perhaps revealing a nervousness and sense of uncertainty around her answer and her interpretation of epilepsy. Nevertheless, these children have demonstrated their substantial knowledge of epilepsy through grasping the significance of the brain and its electrical signals in the creation of seizures. Such knowledge and associated potential understandings of epilepsy and seizures relate to clinical conceptions (Fisher et al, 2017a; see also, chapter 1).

Linked to this, four other children captured the involvement of the brain in their understanding of epilepsy, as Abby stated, "it's like problems that goes with your brain and stuff... and it makes you like wonder around". The problem in the brain causes, presumably, seizures in Abby's grasp of epilepsy. Connected to this, Keira described epilepsy as "it's a sickness. A sickness of the brain", portraying an understanding of epilepsy more connected to the condition as an illness of the brain, rather than a pathological or malfunction of the brain, through lesions for example. The importance

of the brain was seen by Yasmin who initially stated: "*I don't know*" to my question of what she knew about epilepsy, adding later in the interview that it was "*about the brain, I think*". For these children, the brain was the nebulous construct that created and embodied epilepsy in their subjective understanding of their condition.

Aside from knowing physiological aspects of epilepsy, children also connected their understandings of epilepsy to their treatment regimes. In discussing epilepsy with Rosie, she stated:

It means you're on medicine and it means, like, if you don't take your medicine you'll get, like, a sore head if you don't take your tablets, like, if you need it you need to take it, like, if you do need it and if you don't take it you'll really get a sore head.

Rosie has constructed her understanding of epilepsy around her medication treatment and the consequences of not taking them. This was reinforced as Rosie, of her own accord, drew a picture of her 'epilepsy' by drawing a picture of her tablets, describing the drawing as: "*It's me and there's a table... and there's my little tablets. That's what it is. Epilepsy*". A similar understanding of epilepsy was seen by Wayne:

Int: So I am going to say a word now. Can you tell me what you think it means to you? [Wayne nodding] Epilepsy?
Wayne: It's taking tablets.

These responses indicate how children conceptualise and understand epilepsy through a tangible aspect of the condition, namely taking medication. Children's understandings of their treatment regimes will be explored in more depth in the following chapter (5) through examining their experiences of taking medication.

Similarly, a handful of children explained what they understood epilepsy to mean through describing their seizures, i.e. the salient physical manifestation of epilepsy. For example, Emma explained: "*well I would say that epilepsy is like... er, violently vibrating [shakes arms in demonstration]*". Melanie more simply responded to my question of what epilepsy meant to her with: "*it's fits*", and equally Alex stated: "*it's like having episodes*". These insights again connect children's understandings of epilepsy to a tangible aspect of the condition.

Another approach four children used to explain and talk about epilepsy was through metaphors and similes. For example, Lucas explained that epilepsy was, "*it's a party you have in your head...*". Similarly, in this exchange, Mike's understanding of epilepsy was associated with how he and his Mum, Wendy, previously used to talk about epilepsy:

Mike: Well it's sort of like a thing that some people have and, like...
Wendy: What did we used to say it used to make your brain, what was the word we used?
Int: Can you remember?
Wendy: Fuzzy.
Mike: Fuzzy [laugh].
Int: Fuzzy?
Mike: Yeah.
Wendy: Fuzzy brain. That's what you used to call it, yeah.
Mike: That's what it is. Fuzzy brain.

Wayne also repeated the metaphor his Mum had told him to explain epilepsy: "*my mum tells me it fizzes. My head*". The likening of epilepsy and its physiological effect on the body to parties or fizzing can be seen to provide children with an alternative understanding of the condition, providing a pragmatic, and rhetorical, access to knowledge that may not be easily envisaged in reality (Gross, 2013). However, a metaphor or a simile was not always successful in providing an understanding, as became clear as my conversation with Wayne continued:

Int: It fizzes?
Wayne: Which I don't really get what it means, fizz? I'm thinking fizz as like when you shake a fizzy, like, a lemonade and then you open the thing and that sort of fizzy, but I don't know what sort of fizzy means?

This idea of his head '*fizzing*' has confused Wayne, the representation of epilepsy has been taken literally and not been understood nor helped his understanding of epilepsy. Furthermore, it demonstrates that although metaphors can assist in providing explanatory tools for the hard to explain, they may still be 'too' abstract to impart insight and understanding (Buchbinder, 2012). Wayne was questioning this subjective description and subsequent understanding of epilepsy, perhaps in a quest to have a more objective or detailed understanding.

This struggle to grasp what epilepsy could mean or level of understanding was shared. Seven children struggled to explain or describe what they understood by or knew about epilepsy. For example, when I asked Craig, "*Can you tell me what you think epilepsy is about?*", he explained:

Well it means like... it just means something that I know. Like, that might happen. So like I know something might happen to me or something. So like... I can... can't really describe it. [...] I don't know the words to say it

Despite showing an awareness of epilepsy and the unpredictability of '*something*' happening, Craig was unable to articulate his understanding of it in detail. Moreover, Phoebe initially stated, "*I don't know*", when I asked her about what she considered epilepsy to mean to her, before going on to clarify:

Well not very much no cause it sometimes confuses me a little bit because... I know about my daydreams but I don't know how it got into me.

Phoebe's insight revealed the complexities of understanding epilepsy and the different aspects for children to grasp, and perhaps illustrating why other children struggle in understanding. Additionally, where Phoebe's understanding appeared to falter around the aetiology of her condition, could demonstrate an important aspect that children may be unaware of or was not explained to them accurately/appropriately to enable their own understanding.

Similarly, other children replied that they simply did not know, for example Maisie said: "*I am not sure ... I don't really know ...*" and Iain stated, "*Don't really know anything about it. Yeah I don't really know*" in responding to probes around their knowledge and understanding of epilepsy. This could perhaps suggest that these children have not been told, in detail or at all, about epilepsy. Furthermore, this struggle to explain what they understand or know about epilepsy could indicate a lack of awareness and insight into their condition. In my interview with Philip, he explained his struggle with talking about what epilepsy is:

*Int: So... what does the word 'epilepsy' mean to you...?
Philip: erm well. It is a bit hard for me to know to be honest.
Int: that's ok, why is it a bit hard for you to know?
Philip: because of my ... yeah... huh. I don't really feel the effect of it. You know?*

Int: Why don't you feel the effect do you think?
Philip: I don't know to be honest. I just don't.

The reflection from Philip illustrates the lack of tangible and direct experience of epilepsy. The lack of impact of the condition influences how it has been conceptualised: it was a nebulous construct and not something embedded within them. This notion of not feeling the effect of epilepsy could be common for children involved in the study, as most of the children had well controlled epilepsy, meaning that their seizures had stopped or been greatly reduced as a result of successful treatment regimes; as Peter stated: *"I haven't had one for a year so"*. Also, eight children experienced absence seizures which can be considered to have little impact when they occur. It is reasonable therefore that for some the only tangible aspect of epilepsy becomes the treatment regime and or memories of seizures as defining features.

The struggle some children have in discussing and understanding epilepsy could also indicate how infrequently it was discussed with parents. As Emma noted: *"we don't talk about it much"*; and Alex said, *"no we don't chat, nothin to say really"*. It could also indicate the challenge when trying to talk about epilepsy with children, as Courtney mentioned in her interview, *"[epilepsy] is quite scary... I don't like talking about it"*, and Maisie similarly stated: *"I don't like chatting about it so I try not to listen when she [Mum] talks"*. Thus, exemplifying how difficult a subject epilepsy can be to discuss with children.

Most children appeared quite content in their current understandings of epilepsy, as Peter explained, *"I know quite a bit, enough to understand"*. Although this was not universal as David indicated: *"I don't really understand it... I don't really want to"*, illustrating that although he lacked an understanding of his epilepsy, he was content about the knowledge he had acquired. Both Peter and David state that they have enough information to understand epilepsy, to differing degrees, emphasising the individual basis of understanding. Likewise, Yasmin stated: *"I know enough for now... maybe need more when I get older"*, revealing how children might anticipate future needs to alter their understanding, reflecting the dynamic and flexible nature of understanding.

Other children identified gaps and needs for more information on epilepsy at the time of interview. This often was a need for a greater understanding of epilepsy, as Alex stated: *"I think I would like to know it more. Like properly"* and Esther *"I understand mostly. But more would be good, helpful"*. Some children had questions regarding their seizures and what happens during them: *"I don't get how I'm sometimes sick after it, I don't know"* (Peter), *"Like, how hot... how hot do I get? Like, I don't know if I, like, start to sweat and stuff"* (Craig), and:

What I look like when I have one, what do I do when I have one and what do I look like when I have one, am I looking sad or am I looking happy or am I looking straight faced? It's because I can't see myself (Phoebe).

These questions reinforce children's desires to know more about what happens when their seizures occur, in particular what happens to their bodies, physiologically, as well as what they look like during one. They are also, again, drawing on their physical experiences, a tangible aspect, in attempting to understand their epilepsy. A further example of a child wanting such information occurred during Wayne's Mum, Robyn's interview as she spoke about a recent moment Wayne experienced:

Robyn: it doesn't seem to affect him. He doesn't know when he's doing it, he doesn't... he had one on Sunday at 4.20 and it always comes after either a weekend...

Wayne: Did I?

Robyn: Uh huh, I spoke to you, you were standing here and I said 'you've just flickered' and I had to go and write it in the...

Wayne: What do you mean I flickered?

Robyn: Your eyes sort of... they don't go to the back of your head, they go...

Wayne: Can you show me?

Robyn: No I can't do it cause I'm not having an episode. It's your eyes go as if you're blinking really quickly and your eyebrows go up and down and up and down and you go distant, just for two or three seconds.

Wayne: I didn't know that.

Robyn: Well I told you when I went and wrote it on the calendar.

Wayne: No I meant I didn't know what I done.

Robyn: You didn't feel it?

Wayne: No I didn't.

This extract reveals Wayne has very little to no recollection of the episode happening or of it being recorded by his Mum. Although Robyn (Wayne's Mum) does attempt to explain what happened first by giving context, and then a description of what she

witnessed, it is clear that Wayne did not understand exactly what was being explained (particularly illustrated by Wayne requesting a demonstration). To note, all of the children who had these questions had been diagnosed for over two years, perhaps indicating that after an initial period, a deeper level of understanding around seizures could be required.

Children were rarely able to draw on other friends or wider family to enhance their understanding and knowledge of epilepsy. Many children and parents stated that they had no connection with another child or similar families with epilepsy. Only four children in the sample recalled ever meeting someone else with epilepsy. For three of these children, it was a close family member. The fourth had been to an event about epilepsy but had not reflected on meeting anyone else with the condition at it. Seeking out others with epilepsy to meet or talk to about the condition was not mentioned by most children and parents. Mike's parents (Wendy and Don) did, however, speak about their experience of talking with another family with a child with epilepsy:

- Don: we were speaking to another couple in the corridor, like, the waiting room, and he [consultant] came out and he said to us 'don't discuss it cause you've all got completely different types', you know, we were obviously just concerned and asking for... they were the same, they were in the same boat as us.*
- Wendy: They had a little boy as well didn't they?*
- Don: Little boy the same age, yeah.*
- Wendy: And we were comparing notes and we were told not to because they were two completely different..*

By actively discouraging Mike's parents from talking to another family and sharing their experiences, the consultant, at the time, has stopped a potential supportive conversation and source of understanding. This reasoning could be due to the variety of different types of epilepsy, seizures and prognoses, but has the potentially unintended effect of reducing the social support that parents and children can access regarding epilepsy.

The lack of shared insight that could emerge from speaking to others with the same condition as their own was also illustrated by the questions children asked me, as a researcher. At the end of the interview, I encouraged children to ask any questions

they may have, and three children asked about how other children with epilepsy spoke about it. For example, Phoebe and I had the following discussion:

Phoebe: Have you ever met someone else that has epilepsy?
Int: Yes, I've met lots of people with epilepsy.
Phoebe: Do they describe their things differently?
Int: Everybody describes it differently, so you call yours daydreams, I've had people call them funny turns, fits, seizures... what else... moments.
Phoebe: Sometimes I call them moments, I've had a little moment.
Int: Yeah, indeed so lots of different types of things calling them.
Phoebe: That's interesting. I haven't met anyone else before. I think that would be interesting.

Similarly, Esther asked me after the interview as I was leaving whether I had epilepsy, and whether I understood what she had told me. Emma reflected: "*none of my friends have epilepsy so I can't talk to them about it all*". It could be interpreted that such questions and reflections from these children are suggestive of a degree of isolation experienced by the children I interviewed in relation to their condition, as well as perhaps a disappointment at their inability to discuss and in turn be agentic. At the time of writing, there were only two support groups available in Scotland – one for parents and one for young people. There was minimal opportunity for children to meet others with epilepsy or opportunity to seek how others with the condition understand and conceptualise it. This lack of social support, also illustrates the reliance on information obtained by healthcare professionals or parents own learning from alternative sources such as the Internet.

As illustrated, children's knowledge and understanding of epilepsy was varied. It was also unconnected to age, type of epilepsy, or social demographic. Some of their conceptualisations of epilepsy seem based on tangible aspects of the condition that they can directly experience, in particular their experiences of seizures. Other children constructed their understandings from what others have told them about epilepsy. Thus, most of the knowledge and subsequent understanding children hold can be seen through the connection with tangible aspects of epilepsy alongside the use of metaphors (Buchbinder, 2012; Lester, 2009). Both sources provide a (sometimes) concrete means of understanding the concept of 'epilepsy', creating personalised and subjective understandings and meanings of it (Gross, 2011). Although, as illustrated, some children are not satisfied with their own understandings and identify a need for

further understanding, indicating an agentic property to their knowledge acquisition. Attention will now turn to explore the influential factors that shape the understandings that children have.

3. Influence's on Children's Understanding

3.1. Being Told About Epilepsy

It was only through the diagnosis of childhood epilepsy that the majority of children learnt about the condition. At the time of their diagnosis, half of the children reflected on '*being told*' about epilepsy by their parents: "*my mum told me*" (Abby) and "*my mum and dad told me all about it I think*" (Melanie), or by healthcare professionals, as Emma stated: "*I think [consultant] might have told me about it [epilepsy]*". There was very little reflection or thought about what '*being told*' meant to these children, as Alex stated: "*yeah dad told me about it. I think*". The repetition of '*I think*' throughout children's accounts suggested a lack of certainty or that they were unable to remember this moment, perhaps reflecting the importance or significance of being told about epilepsy in their perspective.

Other children spoke about simply not knowing when or how they were told about epilepsy, as Maisie noted: "*maybe someone said it to me and I forget it...*" Alternatively, as Rosie stated: "*I was a baby, I was either one or two*" and Craig said: "*I wasn't a baby... I wasn't like born with it. I think it was a few years into... into my life [laughs]*". With childhood epilepsy predominantly (but not exclusively) being diagnosed before the age of five, it is reasonable to assume that most children would be too young to recall their diagnosis or the conversations associated with it (Hocaoglu and Koroglu, 2011). This could suggest that their age at diagnosis has significant influence on their potential understanding of the condition. Monica, Courtney's Mum, for example, said:

They [healthcare professionals] didn't really explain it to her as such on what epilepsy was or, you know, it was more me they told than her if I'm honest. I can't think of anybody ever sitting her down and saying 'this is what you've got, this is...' you know. Cause as I say, you've just asked her just now and she can't think what... you know, and I was thinking to myself I can't think anybody ever has actually said it's a thing in the brain, you know.

Courtney was diagnosed with epilepsy when she was three years old and did not appear to be involved in the discussions around the diagnosis. Similarly, Sue, Rosie's Mum, when I asked if she felt that Rosie understood what epilepsy was: *"I'm not sure... because she was so small it's kinda grew up with her don't know if we have spoken about it a lot for ages to be honest"*, Rosie was diagnosed at one year old. As children grow up with the condition, it could be seen that minimal attempts are made beyond the initial diagnosis to provide them with information and insight about epilepsy in order to develop their own understandings of their condition. Relatedly, this could also connect with how the condition becomes a part of children's lives as they grow up.

In gaining knowledge and developing their understanding, 15 children recalled receiving written information and resources from a healthcare professional about childhood epilepsy. Lucas recollected: *"I got a diary and lots of bits of paper telling me about it. Mum got different stuff"*, similarly Philip stated: *"I have read all the books about it [...] they are just for me"*. This information was designed for and provided to children, often presented in an easy to understand and digestible format, as Emma added: *"they were easy to read, I got one to give my friends too you know if I wanted"*. There was very little reflection on the value of these books and leaflets had for these children, with most children suggesting that they did not look at them beyond the initial diagnosis period, as Emma added: *"Yeah, I think I might still have them, I'm not sure... they were ok to read once"* and similarly, Maisie recalled: *"I have them upstairs I think. I am not sure... I didn't look at them much"*.

Notwithstanding receiving such information from healthcare professionals, all children viewed, to differing extents, their parents as their primary information source regarding epilepsy knowledge and understanding. Phoebe reflected, for example: *"I talked to my mum about it all the time... she answers my questions about it"*. Similarly, Rosie stated: *"me and mum talk, she telled me about it"* and Craig said *"I ask my mum and dad questions about it"*. These responses demonstrated the significant role parents have in providing information, insight, and explanations about epilepsy, in the past and present.

Seven children went on to add how their parents' knowledge of epilepsy was greater than their own, as Wayne stated: *"my mum and dad would know everything about it,*

not me". Similarly, Alex told me: "*you should ask my dad he'd tell you about it more than I can*" when I asked if he knew what epilepsy meant to him. Such deferring to parents and their knowledge illustrates their role as information providers and gatekeepers. This was not universal however, as (only) Peter added during his interview:

My mum knows a lot, she can explain it to you too. But since I have the fits I would say there might be some hidden things that my mum doesn't know, maybe not know about or something.

Peter thus suggests that having and living with epilepsy has provided him with an additional level of experiential insight and understanding that others, like his Mum, cannot fully understand, explain, or comprehend. The appreciation and valuation of his own expertise created by his lived experiences, over 'learnt' knowledge was very much apparent.

All parents reflected on their role as information provider for their children. Twenty-five parents recalled struggling with knowing how to tell or what to say to children about epilepsy, revealing the complexity of decision-making around the imparting of information about a child's condition. Iain's Mum (Jean) and Dad (Derek) spoke about this:

Derek: I think he gets most of his information from his mum and I and I think he's just got the right amount at the moment because I don't want to worry him. He realises he's got a condition, I don't...

Jean: We've explained to him before that... well I've explained to him before about, you know, why you have tests on your brain, so they can give the right medication and, you know, it's about the brain activity and so on but I don't want to give him wrong information but I don't want to give him too much information, if you know what I mean.

Derek: yeah think that is more than enough... I think he understands that much... not sure...

On discussing what information they gave Iain his parents highlight the balance of providing information that Iain could understand yet not so much to overwhelm and worry him. There is also the hesitation about providing incorrect information, in their attempts to not provide a comprehensive understanding of all that a diagnosis of epilepsy could mean for him.

Given the complexity, the amount of information either given to or withheld from children by parents, varied across accounts. When I asked Wayne's Mum, Robyn if she would want Wayne to know more about epilepsy, she stated:

Maybe I should. I don't mean, erm, I'm quite happy for... er [...] aye I think it maybe would be better so that... you don't know what's age appropriate, you know, I know the stuff that I've read is far, way over his head and wouldn't sink in at all and I don't want to frighten him either, I don't want him to think 'golly is that me?' cause it's...

Hence, reflecting a wish to protect Wayne from the full heaviness and realities of what epilepsy could mean for him. Similarly, during Shona, Nicola's Mum's interview, she stated:

I've never really sat her down and said 'you've got epilepsy'... no, it's good for her, you know, it's good for her we just call them moments.

Shona had decided that it was best for Nicola to refer to her epilepsy and associated seizures as 'moments' instead of revealing more about epilepsy or using the connected terminology. The word 'epilepsy' appeared to hold connotations that Shona did not feel was 'good' for Nicola to be informed of, illustrating a sense of parental protection (Wyness, 2015). This reduced level of information provided to Nicola had impact on her understanding as can be seen through this exchange in Nicola's own interview:

Int: So I am going to say a word. Now can you tell me what you think it is about? [Nicola nodding] Epilepsy?
Nicola: No.
Int: No?
Nicola: I don't know.
Int: You don't know, that's all fine. Can you ever remember your mum, or your dad, or a doctor using that word?
Nicola: I don't know what it is [looks to mum] is that what I call moments [addressed to her mum]?

This quote illustrates Nicola's poor level of understanding and comprehension of epilepsy, as well as demonstrating how influential parents are in providing and facilitating children's understandings and the knowledge they are exposed to. Similarly, Ash, Yasmin's Dad stated: "*Purposely I have not explained to her what happen, I don't want to have her mind on it, maybe in few years maybe I can explain*

what is...". Such comments illustrate how parents' selectively present information about epilepsy to their children, with the aim of shaping children's understandings in ways deemed appropriate to the child's position along the life-course.

Seven parents spoke about withholding particular information. For example, in my initial discussions with Verity (Esther's Mum) regarding taking part in the study, she asked what type of questions and conversations I would be having with Esther. It was made clear that she would not want me to talk about SUDEP (Sudden Unexpected Death in Epilepsy) as she did not want Esther to know anything about it. Later in her interview Verity explained, "*It was hard enough for me to hear that she might die suddenly from it, I certainly did not want her to know*". Other aspects parents held back included the potential for seizures to continue into adulthood and genetic predispositions to the condition. The withholding of information and details concerning epilepsy can be seen to be a form of protection. Specifically, parents seek to shield their children from the subjective impacts predicted to arise as a consequence of full cognisance of the diverse risks associated with epilepsy. Thus, emphasising a vulnerability and reduced competency around children's illness experience. Perhaps, inadvertently restricting their child's agentic potential.

Connected to balancing which aspects of the condition parents told their children was also how parents explained to children about their epilepsy. Wayne's Mum, Robyn explained what she and Alf (Wayne's Dad) had said to Wayne:

We've told him before that his brain can jump and that's what makes his muscles, cause your brain tells your body what to do, and the word we use was to stop the fizzing isn't it, just to stop your brain from fizzing, that's why he has to take his tablets, to stop that. There's probably a more detailed medical explanation than fizzing brains!

Wayne's Mum, Robyn has made use of simple explanations including the imagery of '*fizzing*' to explain Wayne's irregular brain activity and seizures. The phrasing indicates a more "*child-friendly approach to explaining epilepsy, much less scary than words like seizures and electrical activity*" as Craig's Dad, Lee stated. Wayne's Mum, Robyn even appreciated that she was not providing a '*detailed medical explanation*' to Wayne on his epilepsy. The providing of metaphors allows for explanatory frameworks to be used instead of medical explanations, that were deemed unsuitable, whilst maintain a degree of clinical legitimacy in their explanations. The use of metaphors

also controls the information and its presentation (in mundane language and terms), influencing the resultant subjective understanding children craft. However, using such metaphorical language does not always equate with children's understanding, as Wayne conveyed his confusion of what 'fizzing brains' actually meant.

This balance of providing information in an appropriate manner was challenging as Charlotte, Phoebe's Mum, reflected:

It's very hard because they want to understand and you want to explain to them, but at the same time it has to be almost black and white, the explanations, she was having enough trouble to remember most things and understand explanations for everything, so yeah, simple.

This insight from Charlotte reveals that these simpler explanations are perhaps all that children can absorb and understand in the moment. Thus, parents were seen as key to developing and crafting their child's subjective understanding of their epilepsy, through carefully controlling how epilepsy information was presented, interpreted and on occasion, withheld (Singh, 2013; Bluebond-Langer, 2007; Mayall, 1998).

3.2. Parent's Own Understandings

The level of explanation and attempt to provide understanding to children could, however, also be reflective of parents' own understanding and knowledge of the condition. As Carrie and I spoke about epilepsy and how she discussed it with her son, Lucas, she stated:

Well, I tell him about the parties in his head you know but I know it's more than that, but you know I don't know really how else to say it. I don't know if I even understand it beyond that.

Most parents noted that they had a very limited understanding or awareness of epilepsy before the diagnosis of their children; only three parents said they knew about the condition prior to this. For Mike's parents, Don and Wendy, this was due to them both having epilepsy in the family; for Ash (Yasmin's Dad) and Colleen (David's Mum), their understanding was obtained through their careers as health professionals. The majority of parents, though, had minimal awareness of epilepsy prior to their child's diagnosis; as Sharon, Maisie's Mum, stated: "*I knew about it yeah, but that's about it. [...] I knew it was like an illness thing*". These parents, they had heard about

the condition but had what they presented as limited knowledge around what it was or meant beyond being aware of its existence as '*an illness*'. As we will see, the lack of knowledge of epilepsy, or childhood epilepsy, as a condition had implications for how parents came to comprehend the condition and ultimately go on to discuss it with their children.

This initial lack of familiarity with epilepsy meant that many of its early signs and symptoms often went unnoticed or were explained as something else by half of parents. For example, Charlotte, Phoebe's Mum, reflected:

It took a long time for us to understand what was going on, we just thought she was daydreaming and just not with it really and I just thought 'this isn't quite right?' cause a lot of people say to you as a mother 'oh my child's always daydreaming, all the time' and you think well maybe this is what's going on, but it wasn't obviously, but it takes a while, you know, and then you suddenly pick up this isn't right.

Charlotte's explanation of absences as '*just daydreaming*' and something that children do, offers a benign, everyday reason for its occurrence. It was only as these events continued that she began to appreciate that something more serious was happening, but even then, it was just that something '*isn't right*'.

Similarly, Jean, Iain's Mum, recalled:

I noticed just his head twitching and had never noticed it before and then we kept an eye on it for a good few months and we thought it was like a bad twitch, went to the GP and the GP didn't... because it only lasts a few seconds it's very hard.

The low impact and short duration of the twitches meant that they were challenging to explain and understand, for both Jean and the GP. Similarly, children also struggled to understand what was happening initially. Phoebe also recalled her early events, but only after they had become more frequent and disruptive:

I got really upset because I kept on panicking about what they were and mummy thought I should go to the doctors, and I was reading a book and every time we turned a page I was having one, every time I read a word I was having one.

The upsetting nature of these unknown, disruptive events, for both adults and children, was clear.

For nine other children, their initial symptoms of epilepsy were more significant but not necessarily immediately recognisable as epilepsy for parents. For example, Christine, Lily's Mum, recalled: "*Oh God, the first time. Well. It was at night I just well. She was all over the place [Mum shakes her arms and legs in demonstration] I just didn't know what was happening*". The lack of understanding as to what was suddenly happening created great uncertainty and concern. Likewise, Verity, Esther's Mum, described:

she really just had a long time staring and then felt a bit sick and of course this is totally out of the blue for us, so felt a bit sick and then was sick and then jerked for about... so she had a, well what we now know was a tonic clonic for about one minute and then she came round quite quickly [...] it was terrifying, watching that.

Verity's vivid account demonstrated the shock and awe a seizure can cause. The addition of the clinical phrase '*tonic clonic*' and its qualifier that '*we now know*' indicates the lack of understanding and knowledge around what happened initially; it is only after the event that this information was learnt and retroactively applied.

Even when a diagnosis of epilepsy was made, many parents still expressed concern of what it meant, both as a condition and for their child. Shona, Nicola's Mum, reflected:

Yeah [consultant] diagnosed her with epilepsy and told me the news and yeah, it was really difficult. Really difficult. And plus, you know, you're kind of... you don't know, well at that point in time I didn't know anything about epilepsy, well I kind of knew that... my definition of epilepsy was that someone would collapse and have a full on convulsion, so I think that's what goes through everybody's mind really isn't it... until you actually do a bit of research and you think well wait a minute, there's... you know, there's different forms of it.

Shona's previous lack of understanding and the assumptions she held of epilepsy as a condition has affected how she understood and felt about Nicola's diagnosis initially. The lack of understanding also influenced how parents began to attach meanings to the condition and what this could mean for their child, as Sue, Rosie's Mum said:

the diagnosis was quite difficult because even though I've heard of it I never kinda knew anything about it and the only bits I kinda knew was the pretty negative, all the things she couldn't do, that she wasn't going to be able to do, so that was the kinda first thing that the doctor had said, she said that she'll [Rosie] never be a fighter pilot or pilot and I got really upset.

Sue's initial '*pretty negative*' understandings of epilepsy have influenced how she has conceptualised the diagnosis and the perceived implications for Rosie's future. Similar moments were seen across ten other parents' account as they recalled the diagnosis period. These thoughts are connected to a lack of understanding and knowledge of childhood epilepsy and what it could mean for children and their parents. This initial reaction can influence the meanings parents attach to the condition and consequently how it can be incorporated into part of their lives. It can also be a signal to level of understanding they wish, or do not wish, for their children to have, linking to the previous section.

In attempting to understand the diagnosis, all the parents reflected seeking information to learn about epilepsy. This thirst for information was seen to varying degrees, for example, Verity, Esther's Mum, "*I had an absolute ton of questions, I mean I just kept firing them at her [ESN] bless*", whereas Sharon (Maisie's Mum) recalled: "*they probably have given me booklets when she was first diagnosed and I mean I never read it all I knew was that is what she is taking like medicines and why*". The need for information was apparent and sought to contextualise epilepsy for parents, but the depth and detail of such information needed was seen to be very different, and individual, across parent's accounts.

As parents learnt more about epilepsy, they created a broader understanding of it, as Marcus, Alex's Dad, reflected: "*aye I read all about it. From everywhere [...] I understood it more and you know what it meant*". This search for information was familiar across the majority of parents' accounts and encompassed many different sources. For example, Charlotte, Phoebe's Mum: "*lots of leaflets and I think I did quite a lot of reading online*", and Cathy, Melanie's Mum: "*we got a whole lot of information right at the beginning like papers and stuff, I mean, [ESN] was also absolutely brilliant with information*", highlighting leaflets, online written resources and healthcare professionals as sources of information. No other sources of information were mentioned by parents, even when prompted.

Two parents were, however, critical at the lack of specific materials and information provided on the different types of seizures, as Ellen, Philip's Mum reflected: "*Yeah they were ok, it's more for those that have fits. And Philip has never had a fit*". Philip has absence seizures, compared to tonic-clonic seizures. Wayne's Mum, Robyn reflected on what this meant for others understanding of epilepsy:

everything we'd been given it was all tonic clonic and then a little bit at the bottom about absence seizures, nothing about the jerks [...] I wish I could get some leaflets to hand into school cause they say 'oh he's epileptic', 'no it's not that type of epilepsy, it's a different type', they can't cope with it.

The lack of appropriate information on the type of seizures Wayne experiences has consequences for how his teachers understand, and potentially how they support him. Wayne's Mum, Robyn also reveals the assumptions others hold regarding epilepsy and the lack of broader understanding around the different seizure types and complexity of epilepsy as a condition.

Parents' desire for information can, though, come at a cost, as Craig's Mum, Annie reflected:

you can go on the internet and find out about anything you want to know but it terrifies the life out of you. In fact, that's another thing that [ESN] told me not to do, to stay off google. And that was really good advice actually. Because you...can... [exhale of air].

The impact of learning more about epilepsy and searching for such information can be terrifying for parents. The Internet provides an abundance of knowledge and insights, but it can also provide too much information and detail for parents. Reflecting on this Charlotte, Phoebe's Mum similarly added: "*yeah useful and scary all at the same time, like any diagnosed illness, you know, internet is... yeah...the worst place in the world*". The range of information, support and advice which can be suddenly accessed via the Internet dramatically increases, appearing chaotic and overwhelming.

Yet, the information produced in leaflets given to parents at diagnosis also caused similar reactions. Ellen, Philip's Mum, reflected on the information healthcare professionals provided her:

we were given lots of leaflets when he was first diagnosed. We had a scary one. The risk of sudden death. That was like [horror face] Oh my god. It totally freaked us out. It shouldn't ever happen, but wow.

Gaining such detailed, and potentially life changing, information regarding epilepsy can scare parents, particularly during the sensitive period around diagnosis.

This over exposure to information resulted in eight parents limiting their quest for information and understandings of epilepsy. Verity, Esther's Mum, reflected, for example:

I keep thinking just don't ask too many questions because we don't really want to know, I mean, I did read the Epilepsy Scotland website but I would not Google risks of epilepsy, no I wouldn't do that. I've learnt that.

Verity has '*learnt*' from past attempts to learn more about epilepsy. Her quest for information has been curtailed by her wish to not know the potential outcomes and consequences of Esther's epilepsy and what it could mean for her. This could reflect Verity's wish to remain ignorant perhaps. This was also seen in a handful of children's accounts as Esther stated: "*I never really wanted them to give me any information about it*". The wishing to remain ignorant can, however, be useful despite the initial assumption of disengagement. It can be a tool to deflect attention from the unknowns and uncertainties, offering a sense of protection.

Moreover, the negative reaction to certain aspects of information about epilepsy could influence what parents feel willing to tell their children about the condition. As was illustrated above, some parents chose not to tell their children about SUDEP or other potential outcomes of their seizures. Again, this can be seen to protect children from the realities of the condition in parents' selective presentation of knowledge to children; for example, Christine, Lily's Mum, spoke about cleaning up after Lily has a seizure:

she wets herself you see so I put her in my bed, then I get all the bed sheets off and washing before she gets up again. I don't want her to see that, but would it make it better for her to know... I don't know.

The selecting of what and how to tell children about their condition was challenging for parents. Again, parents only offer, positive subjective insights and information and

minimal factual knowledge. This enables more positive meanings of their epilepsy to be drawn and created by children.

A handful of parents indicated that they needed assistance in telling children about their condition and in providing them information about it. For example, Christine, Lily's Mum, considered:

it's trying to sort of explain more to Lily what's kinda maybe going to happen to them and, you know, how long she's gonna maybe have it for and things like that, I think I need ... Parents are fine, we can just go and look it up on the internet and that, but more the children I think should get more help.

However, three parents did reflect that they would not appreciate any assistance from healthcare professionals or others in this regard. Geoff, Keira's Dad reflected, for example: "*I wouldn't really be that interested in what other people thought I should be saying to my kid about her epilepsy*", illustrating potentially contradictory findings about who should be providing children with information about their epilepsy. Although, as has been shown, parents gather information from a variety of sources; interweaving it into their understandings and discussions, consciously and otherwise. Geoff's reflection could nevertheless illustrate potential challenges for healthcare professionals in providing information to children and their parents, reinforcing parent's status as gatekeeper for information, as well and how information on the condition could be shared and discussed with children.

In summary, despite various interactions with healthcare professionals, the children I interviewed presented their parents as the primary source of information about, and consequent understandings of, epilepsy. In doing so children overlooked their varied, experiential experiences of their condition. This follows other studies on information provision and childhood epilepsy (Harden et al, 2016; Lewis et al, 2010). Parent's own understandings were shaped from identification of initial symptoms and the diagnosis period where information was readily available, crafting meanings and conceptualisations of epilepsy. The availability of information can, however, overwhelm and scare parents as the informational knowledge appears removed from their own context, explicit and overly detailed, reducing parent's ability to reflexively engage with it (Nettleton and Burrows, 2003). This could also be seen to influence the information they provide children, impacting strongly on the meanings children

created around epilepsy. Thus, the (carefully controlled) communication of information from parent to child could provide a potential explanation for children's level of understandings, knowledge and meanings they attach to their epilepsy.

Consequently, understanding can be considered an interactional construct: its acquisition is dependent on the passing of knowledge from parent to child, and child to parent in respect to experiential experience (Wyness, 2015; Benson et al, 2017). How parents' view children's experiential experience is however under-appreciated in this sample, alongside their lack of considering information provision as a form of agentic development. Similarly, the information and understanding needs of children has shown to be not static; rather, it shifts and changes as the child grows up and questioning their experience and knowledge gaps. The meanings and impressions children hold around epilepsy and the experience of it through seizures will now be explored.

4. Children's Experiences and Impressions of Seizures

How chronic illness is experienced can reveal an important component of how it becomes conceptualised and made sense of more broadly (Bury, 1991). This section will explore children's impressions of epilepsy and experiences of seizures, and how they attribute meanings to these happenings. The implications this has for their conceptualisation of epilepsy, their involvement in treatment and management, and opportunities for agency will also be drawn out.

Most children stated that they had minimal thoughts or feelings regarding their epilepsy, as Susanne explained: "*[Epilepsy] it's... kinda... It's just there*" and as Phoebe stated: "*It makes me feel... makes me feel okay*". These reflections indicated a sense of apathy in terms of epilepsy – its presence has been acknowledged but beyond that there was little consideration, which they wished to share, in how they regarded the condition.

Seven children however stated that they did not want to have epilepsy or seizures anymore, as Iain stated: "*well I said to my mum before you came that I wish I didn't have it*". Others made similar statements: "*I'd rather not have epilepsy, it's just annoying*" (Esther), "*I don't want it [epilepsy]*" (Maisie), and "*Well I don't want epilepsy*

[...] *it makes me upset*" (Keira). Abby reflected how she felt "*pretty sad because I just want, because I just don't want to have it and happen to me.*" These assertions made it clear that they simply did not want to have epilepsy. Yet, there was minimal reflection on whether there were any specific aspects of epilepsy or its treatment and management they would prefer not to have, or whether it was the condition as a whole they did not want to have. This view was primarily, but not exclusively seen, in children with limited seizure control.

Despite seven children explicitly making such statements about their feelings of having epilepsy, caution should be taken in taking this number at face value. In particular, five further children were due to stop their treatment regime within the following few months after their interview, since their seizures had stopped for nearly two years. Accordingly, any negative perspectives on epilepsy could have faded over time, relative to when they were experiencing a more 'active' period of the condition. Jack was one such child; he was due to completely finish his treatment regime within a week of his interview. When reflecting on epilepsy, he stated: "*I don't think I will ever be fine about it but you I am better about it*", perhaps illustrating a sense of acceptance with the condition and the associated treatment and management.

For the vast majority of children there was no warning of when a seizure could occur. Most seizures occurred unexpectedly: "*It just happens*" (Yasmin) and "*it surprises me*" (Mike). Seizures just happen, they often cannot be planned for, though some may be aware of triggers. Even when some children and parents became aware of specific triggers, as discussed above, there can be uncertainty about when they happen. For example, despite knowing that his 'shakes' are triggered by loud noises and becoming startled, Iain still spoke about the unexpected nature of having one: "*well sometimes they just happen at school, just randomly, but when like the teacher shouts at someone or, say, she shouted at me or something, I'd get a wee... I might get a wee bit of a fright and then start, like, having a wee shake*". Irrespective of knowing the trigger, Iain still finds that his shakes can still occur '*randomly*'. Even when discussing this, Iain corrects himself suggesting, that the shouting '*might*' cause him to have a shake illustrating the associated unpredictability. There is a level of uncertainty around when they happen in Iain's reflection.

Notwithstanding the uncertainty, many children were able to describe what they considered happened during a seizure. The majority (nineteen) of children's discussions centred on physiological or physical descriptions of what they perceived happens to their body as they experience a seizure. Courtney explained "*I go all dizzy and then I normally go to sleep and then when I wake up I can't talk and I feel sick and I get all numb*". The seizure has (physiologically) changed her body and her experience of her body, bringing with it powerlessness – going to sleep, being unable to talk or feel anything. This sense of change being triggered was illustrated by Jack: "*hum probably makes me act a little different*", suggesting a potential unknown change to his behaviour. Similarly, Melanie recalled:

it goes all shaky and wobbly [Int: which part of your body is it?] my whole body. I think it was, can't remember.

Connected to this bodily experience, the head and eyes were frequently specifically mentioned by children as key aspects of their descriptions of seizure experiences. Alex explains his experience:

Alex: Er... Your eyes go funny.

Int: Your eyes go funny? What happens when they go funny...?

Alex: They go like that way [eyes divert left and he stares in to the distance]

Alex detailed his absence seizures by the moving of his eyes - providing a demonstration of what happens when he experiences a seizure. Yasmin explains her loss of vision when she experienced a seizure: "*when it came I can't see anything then I can only... like, I can't see anything*". Similarly, Rosie: "*I get a sore head*" and Emma: "*it's like a feeling in... it's almost like a head rush that doesn't tickle*". Both Rosie and Yasmin described their seizures as being only in their eyes or head respectively. It is less about the whole body, but more specific aspects. This distinction perhaps reflected the different seizure types and how they are experienced by children.

Likewise, Phoebe connected her seizure to her brain: "*it makes me feel quite dizzy and while I'm having it, it makes me feel blank and my brain stops working, like, everything stops working*". Phoebe added that this made her body stop working during the seizure further indicating the overriding and important nature of the brain in epilepsy. Three other children also reflected a lack of something happening during a seizure. Craig detailed: "*when you're having it, you feel... you just, feel, nothing*", there is

nothing to feel or to note as the seizure happens for him. This lack of consciousness and nothingness was similar to feeling tired or going to sleep which was experienced amongst ten of the children: "*It's when you stay up for a bit and then you just wipe out and want to fall asleep and so. And then you when wake up you don't know what happened so you fall asleep*" (Abby). Abby explained her seizures through states of sleep, suggesting her seizures cause her sleepiness, and perhaps alluding to a level of unconsciousness that her seizures bring.

Children's post-seizure experiences varied with seizure type. Ten children spoke about '*waking up*' afterwards, reinforcing an idea of a seizure causing unconsciousness. Keira recalled after her fits: "*It makes me very exhausted when I wake up*". The notion of '*waking up*' afterwards could be seen to be an approach to normalise the experience of seizures: they '*wake up*' after sleeping which is natural and expected. The use of everyday concepts to understand what was happening was shown, illustrating again how children conceptualise what happens after a seizure through finding tangible meanings, terms and explanation for this strange behaviour. There were no discussions or indications of *not* waking up after a seizure. This could also perhaps indicate a lack of awareness of the potential severity of some seizures in children's understanding of the condition and its potential consequences, namely Sudden Unexpected Death from Epilepsy (SUDEP).

Most children spoke about being able to, "*go back to normal*" (Yasmin) or were "*just fine after that*" (Mike) after their seizures. As, Maisie explained in more depth:

Maisie: then just you know shake ... shake it off.
Int: Shake it off?
Maisie: Yeah like, I'll just be like what happened just there I then just forget about it and keep on running

These children were able to '*shake it off*' and carry on with what they were doing. These seizure experiences appear to have minimal impact and no significant disruption on their life at the moment of occurrence.

Yet, this was not the case for six children. As Peter explained:

then I suddenly wake up and sometimes it's like something that... it's a day that I'm really looking forward to it and then I can't really go anymore cause I'm in the hospital.

After a seizure Peter was unable to carry on with his day, the seizure was disruptive and often resulted in a trip to the hospital. Also, shown was a sense of disappointment at the disruption and consequences of having a seizure, revealing the impact of the unpredictability of seizures. As Peter illustrated, going to the hospital after having a seizure was common across these children's accounts; for example, when I asked Esther what would happen after a seizure, her response was simple: "*I'm in the hospital afterwards [shrugs]*", alluding to a sense of normality regarding the visit to the hospital afterwards, there were no exceptions. Although the seizure causes a disruption to their normal day, there is a different sense of normality that has been created around what happens after a seizure.

Despite the experiences illustrated so far, not all children wished to discuss or could talk about their own experiences of seizures. When asked about her fits, Keira stated: "*I don't want to er... [turns thumb down] better forgetting them*". Keira's strength of feeling illustrates the discomfort some children might experience in talking about seizures. Similar sentiments were more clearly illustrated and by more children when discussing seizure activity in context of clinic appointments which will be explored in the chapter 7.

Instead of talking about her moments, Maisie used a picture to draw what happens when they occur as she could not find the words. She explained to me: "*this is what my face looks like when I have one*". Whereas Lily and Nicola were both unsure how to describe the experience and simply stated, "*I don't know*" (Lily) or "*er, don't know*" (Nicola) to my questions about what their seizures felt like; neither wished to draw a picture. Similarly, Wayne responded: "*I don't know, nothing happens [shrug]*", to probes around experiences of seizures. The additional comment that '*nothing happens*' could reflect how absences and myoclonic jerks, which he experiences, can often go unnoticed by children given their lack of impact and fleeting nature. This could also suggest why some children can appear to fail to explain what happens when their seizures occur, as could their lack of consciousness during a seizure.

The suggestion that these children were the only children in the sample to find describing, recalling, or discussing their seizures as troublesome could be somewhat misleading. Rather, three children spoke about their experiences through descriptions others had provided them, instead of drawing on their own direct experiences. For example, when I asked about what happens when she had a seizure, Keira answered "*Mummy and daddy say I make a weird sound*". Her parents had informed Keira of what happens, she does not offer any of her own insights just those that her parents have provided. Connected to this, much of Emma's accounts of what happens when she experiences a seizure is gained from others: "*Well you can't feel anything, like, and you can't see anything cause my eyes were, like, rolled back or something... and apparently I was drooling or something, couldn't feel it [...] Apparently I either, like, fall on the floor or do something like that*". Emma reveals that she does not feel or see anything, but her understanding of what actually happens is provided by what others have told her – '*apparently*'. Again, Emma's reflection demonstrates the role others – particularly parents – hold in providing information to children about seizures and the missing information and details that children can be unaware of whilst experiencing a seizure. Thus, being told about their seizures by others had an important influence on the meanings children attributed to their seizures.

When discussing their thoughts and feelings about epilepsy, many children discussed their feelings towards seizures specifically, and what having seizures meant to them. Replicated across most children's accounts was a notion of being scared after experiencing a seizure: "*I'll just be like a bit scared and... don't know*" (Yasmin), "*like I am scared...really upset....*" (Maisie). Moreover:

Int: *How do they [seizures] make you feel when they happen?*
Courtney: *Scared.*
Int: *Scared?*
Courtney: *Yeah really scared.*

Similarly, seven children also used an emoticon depicting 'scared' (by their own definition) on their spider diagrams. Peter's reasoning for picking a 'scared' facial expression was explained: "*That's scared. Because I'm scared when I wake up [afterwards] and kind of shocked*". The reiteration of being scared after seizures could illustrate an emotive reaction to the sudden and unexpected nature of seizures as well as indicate the surprise at the physical and physiological changes that occur when

they do happen, as previously described by children. The addition of 'shocked' in Peter account further supports the sudden and unexpected nature of seizures; they are rarely expected or predicted.

The unpleasant nature of the seizures was also reflected in children's feelings. Nicola stated, for example, "*Sometimes they're horrible*". Connectedly, Emma stated:

Emma: I'm maybe even angry with them.
Int: Yeah, why are you angry with them?
Emma: Because they feel horrible and they're not nice and it's like a horrible child at school, it's like if... a horrible child at school makes you feel horrible and isn't nice they make me angry.

For Emma the unpleasant nature of her seizures has created feelings of anger. Emma's comparison of seizures with a '*horrible child at school*' also reveals perhaps a sense of unfairness and lack of control of having seizures.

Furthermore, when discussing seizures, Jack wrote on his spider diagram "*concerning*" and "*embarrassing*", with the latter underlined twice. As we spoke about the words, Jack said "*well it's just that you never know when it's going to happen so...*" going on a moment later to explain: "*well if you could like have... like a watch to say you going to have one you know or something... then I could not go to school so I wouldn't get embarrassed and stuff*". The uncertainty around when a seizure could happen was '*concerning*' and intrinsically linked, for Jack, with being embarrassed. He does not want to be seen having a seizure. This was particularly sensitive in a school setting as Jack stated, potentially suggesting the presence of friends and peers could make it more embarrassing or concerning for him. Similarly, Susanne also described: "*I am not upset about them but I... I don't like, like having them... so much... I am embarrassed at them...*", thus reflecting again a sense of embarrassment associated with seizures. Such insights suggest that experiencing, or being seen to have a seizure, was something different or unusual that others perhaps would not understand when witnessing them.

Connected to this, five children recalled seeing a video of themselves or someone else having a seizure, as Courtney and I discussed:

Int: Have you ever seen a video of someone having a fit?

Courtney: [Nods]
Int: Yeah?
Courtney: Mum took one of me once...
Int: Yeah...? What was that like?
Courtney: Scared because I couldn't remember having it.

Courtney's feelings can be seen to reflect the unconscious nature of seizures, but also, more fundamentally a video reveals what actually happens during these moments and for Courtney, this is scary. This revelation of what happens was too much for Courtney, perhaps reflecting an aspect of the condition that perhaps children would rather not understand or be made aware of.

Healthcare professionals do, however, ask parents to record their children's seizures to assist them in diagnosing specific epilepsy types through particular seizure presentations. This request could mean that children can become aware of such videos being produced and held by parents, creating a potentially upsetting discovery for children, as Yasmin stated: "*I don't want to see it*". Sixteen other children agreed that they did not want to see a video of themselves having a seizure, with many responding simply: "*No. No way*" (Susanne); "*I would rather not*" (Esther) and "*Nope, no... no*" (Lily). Peter provided slightly more insight:

Int: Would you want to see somebody?
Peter: No.
Int: Ah, why not?
Peter: Cause it doesn't look very nice.

Peter's reasoning demonstrates a desire to not have that level of insight into his seizures. Such conceptualisations and thoughts of seizures experiences can influence how they view the condition and how they incorporate it in their lives. It also reflects the potential concerns raised by children of being seen having a seizure and the embarrassment this could cause them. Phoebe was the only exception to this strong distaste for seeing themselves having a seizure, stating: "*I think it will be quite interesting because I've never seen it before*", indicating a sense of curiosity about seizures and what happens that was not seen in other children's accounts. Phoebe raised a number of further questions during and after her interview, indicating a general quest for more information and a deeper understanding of her epilepsy.

These conceptualisations of epilepsy and interpretations of their seizures can be seen to create negative interpretations and impressions of epilepsy by children. The negative interpretations of epilepsy and seizure experiences led a number of children to express notions of being different, as Emma noted:

I feel slightly different in the way that nobody else in my class has it and in that way it's also a big thing, and a big thing also because it does, like, take up quite a bit of my life sometimes.

Similarly, Craig stated: "*I feel different to him [brother], you know cus of it [epilepsy]*" and David stated: "*I kinda feel a bit different to them*". These feelings and ideas of being different illustrate, that to these children, epilepsy is different and not 'normal' when thinking of others such as their friends, peers and siblings.

In sum, children's experiences of seizures inform how they come to understand, conceptualise and attribute meaning to seizures and importantly, what happens to them when they occur. Most children viewed and experienced seizures as fleeting events and moments that passed with little disruption to their lives. The disruption that others experienced, however, created a new normal routine in the wake of their interruptive presence. It can also be seen how these experiences of seizures can have implications for how children feel about epilepsy more generally. This sense of acceptance replicates previous findings of children's experiences of epilepsy (e.g. Elliott et al, 2005; Moffat et al, 2009). The influence that others, primarily parents, have in shaping children's understanding of seizures was again also seen, and appeared fundamental in children's assembly of self-knowledge and understanding of their epilepsy.

Children's understandings of and the meanings they attributed to seizures also merged to create their impressions of epilepsy and how they viewed it in the context of everyday life. Most children hold negative impressions of their epilepsy and the connected associations of what it meant for them to have epilepsy and be seen to have epilepsy by others. This connects to previous findings of children and parents holding stigmatising feelings around epilepsy (e.g. Harden et al, 2016; Benson et al, 2017; O'Toole et al, 2017). If and how children inform others of their diagnosis, offers a further significant dimension of exploring children's conceptualisations and contextualising of epilepsy in their lives.

5. Disclosing Epilepsy

Given the nature of epilepsy, in particular seizures, it can be challenging to control who becomes aware of its presence and when. Coupled with this, understandings of epilepsy in the wider public can often mean that even when seizures occur or a diagnosis revealed it can be misunderstood (Bishop and Allan, 2003; Schneider and Conrad, 1983). Despite this, how, when, and why children chose to disclose their diagnosis of epilepsy to others offers further insight into their own understandings of epilepsy and what it means to them.

Most children stated that their friends or peers knew about their epilepsy. Many children recalled lists of friends who knew about their epilepsy, as Philip stated: "*all my friends know about it, like at school and around here*", and Alex said: "*[lists off six friends] they are like my good friends, they all know about it*". There was little reflection by children on what *knowing* about their epilepsy actually meant and how these friends had come to learn of their epilepsy. Connected to this, two children added that their friends were aware of their epilepsy but had not seen them have a seizure, as Craig said: "*these are my like closest friends, they get it... I don't know if they've seen me though... you know have one*". This could perhaps indicate that although there was an awareness of the condition within friendship groups, there may not be an understanding or an appreciation of what epilepsy means in terms of seizures and treatment regimes. Connected with this, children may also struggle to explain epilepsy to others, in their attempts to make them aware of the condition. As Rosie stated: "*I told them [her friends] like I told you [pointing to her picture of her and her medications]*", perhaps illustrating that children are not necessarily able to provide an account of epilepsy that would allow their friends to comprehend and understand the condition. This is particularly evident, given their own lack of understanding as previously illustrated.

Five children stated that only their best or closest friends knew about their epilepsy diagnosis. As Phoebe spoke about telling her best friend:

Phoebe: I've told her a lot about it and she's the one I can trust.
Int: Oh that's good. Would you want everybody else at school to know?
Phoebe: No because they'll start talking about it and whispering it on, it's mainly a little secret that I keep.

Phoebe went on to explain:

I don't really tell my friends about my epilepsy, I normally just keep it to myself because they may not understand [...] it takes a long time to explain [...] I definitely don't tell the boys anything, they'll probably laugh or something.

This concern of not wanting others to know and keeping it a secret was seen in regard to a fear of what others would make of the condition and their reaction to learning of it, namely laughing at Phoebe. This understanding was seen by Susanne who explained: "*Only my best friends know [...] cus they understand it*", indicating that only 'best friends' appreciate and understand the condition and what it means for Susanne. Similarly, Emma reflected on what telling only close friends meant to her:

they know that it happens and I'll, like, on days when I have to go to the hospital for a check-up, I'll say to [friend] my friend, my great friend, like, my best friend [laugh] I'll say 'I'm going to be going to the hospital today, like, before lunch, just before lunch, so I won't be able to be with you for that part of the day' and she'll understand, she won't be like 'eh, why?' or anything like that, she knows why.

The importance of their friends *understanding* their epilepsy was paramount, providing potentially a sense of support to these children. Perhaps also connecting and emphasising their lack of social support from others with epilepsy, as discussed previously. This insight also reflects the stigmatisation that children feel around epilepsy and the importance they place on keeping it a secret, and or only having trusted friends aware.

For some children, there was a practicality in their friends being aware of their epilepsy. Peter, for example, stated: "*all my friends do [know about epilepsy] because if I'm out playing with them and something happens, they might have to do something*". This sense of practicality was more apparent in parent's discussions of disclosure; for example, Wendy, Mike's Mum, stated: "*we made sure all his friends parents knew, you know, just in case*" and Christine, Lily's Mum: "*Oh the whole neighbourhood know, if anything should happen*". Resonant with children's accounts, this *knowing* was seen as a requirement to keep them safe should a seizure happen beyond the family home. This practicality connects to managing the impact of the uncertainty of when seizures can occur, which will be explored in more depth in the

next chapter (5). Conversely, however, Craig's Mum, Annie spoke about wanting others to be aware of epilepsy to understand the differences Craig experienced:

it was quite important. I wanted the school. I wanted the children to know a little bit about it... and that sometimes some boys and girls might behave a little differently and it's not because they are being bad... it could be because of a medical... epilepsy...making them act different.

Consequently, for some parents, disclosing epilepsy could be more about getting others to understand and accept the condition and what it means for their child, rather than for practical or safety concerns.

Choosing whether or not to tell friends or others about their epilepsy was not always the children's decision however. For two children, their epilepsy was revealed by others; as Keira explained:

Keira: I think they [classmates and teachers] know because last time at school daddy was saying about the fits [shakes head, looks down]
Int: Is that not good...? Do you wish he didn't tell people?
Keira: I think it wasn't good at all. The more he said it the more it made me upset.
Int: ... Why do you think he told your teachers?
Keira: And the classmates... because in case I have a fit

Geoff, Keira's Dad, had chosen to disclose Keira's epilepsy; this had natural implications for her. The upset caused by this disclosure was clear, but also suggestive of Keira's desire to keep her condition from those in her class and not wishing to be seen as being different perhaps. Similarly, Lily mentioned: "*teacher said it to them [Int: to who?] everyone in my class*", revealing a lack of control in the disclosure. Lily added later: "*but they don't really care*", reflecting less of a concern that others were aware of her diagnosis. Further suggesting that feelings of difference because of their epilepsy may not be universal.

For others, their epilepsy diagnosis was difficult to hide, given their seizures. As Iain stated: "*Well the class all look at me...*" for Iain his whole class knows about his epilepsy because he cannot hide his shakes. The whole class can see them as "*that's mostly where it happens*". Iain went on to explain what it was like:

Well there's loads of people around me and they're not really... most of them can't see it cause they're playing, but I sort of think 'oh no I'm having one, why could it happen in the playground just now?' and I sort of like don't want to have one especially not at this time when there's lots of people around.

The desire for his shakes to be less noticeable was clear; Iain also revealed a sense of embarrassment and lack of control over them, reflecting previous thoughts by other children with regard to the uncertainty of their seizures. The uncertainty of seizures exacerbates the negative feelings and felt-associations children may have regarding their epilepsy.

Five children spoke about hiding their seizures from others. Maisie stated:

I just... just ... pretend I was thinking or looking at something so they don't. Cus if they just say something. Sometimes that happens. Everyone looks... so... I pretend... I was lookin at something else.

Maisie hides her moments from everyone, adding later, "no I wouldn't tell her [teacher]... I would tell [younger sister] to keep it to tell mum at the end of the day...". Maisie reveals a great degree of secrecy around her moments and a need to keep it quiet from all those around her. Susanne also recalled a similar approach, "if I am at another person's house ... I wouldn't... I don't know... I won't tell... them... I don't know". Yasmin also mentioned: "only teachers know... I don't want anyone to see me". Likewise, David recalled leaving a school assembly to avoid others seeing him have a seizure, which reveals a benefit of having auras, a warning before a seizure occurs. These insights reflect an embarrassment and perhaps a fear of what others will think or how others will react upon seeing them have a seizure. Thus, some children would rather keep their epilepsy diagnosis a secret, constructing the condition as a private and deeply personal matter. Also, revealing an interpersonal and potentially internalised sense of stigma around their diagnosis and display of agentic behaviour of self-protection.

The concern of what others would think of the presence of epilepsy was, in some respect, mirrored by a handful of parents as they recounted other people's responses after being told about their child's epilepsy. As Shirley, Abby's Mum, recalled, for example:

well the teachers were fine, they were fine, but some of the other parents were a bit erm... one parent in particular who erm you'd think I had told that she [Abby] had an infectious disease she was a bit like oh gosh oh no oh gosh. You know as if her daughter was going to catch it. Oh we had words... I got so upset with them. [...] I even told her that it was a disability!

Similarly, Jean, Iain's Mum, said:

I was furious, I had to remind her that she shouldn't be talking like that to her kid, as the kid was saying all of it again in the playground. [...] He [Iain] got picked on cus of that. The school thankfully shut it down though.

The realities of disclosing the condition, revealed others' detrimental misunderstandings and reactions to the condition. Despite this, all parents disclosed their child's diagnosis to teachers and parents of their child's friends, again emphasising the practical need linked with safety concerns.

Who children (and parents) chose to disclose their epilepsy to has been shown to influence how it is integrated into their lives, as well as having implications for the management of seizures. With usually only trusted friends made privy to their diagnosis, children's subjective understanding and impressions of epilepsy are seen to be one that requires secrecy. This reveals an interpersonal and potentially, internalised sense of stigma around their own diagnosis (Jacoby and Austin, 2007). Even when their seizures prevent this secrecy, a sense of upset and feelings of difference have been shown – children are aware that their epilepsy identifies them as different to others, irrespective of the nature of their seizures (Benson et al, 2017). The reinforcement of this from parents' accounts reflects this also, as well as the underlying lack of understanding and knowledge of the condition in the wider public and associated stigma (Bishop and Allan, 2003).

These secretive practices around their epilepsy and its disclosure are also demonstrable of children's agentic potential: electing to obscure their symptoms and signs of differences. Consequently, indicating children's attempts to protect their sense of self, internalising stigma traits, through agentic behaviour. This also demonstrates how opportunities of agency can be circumstantial and not always universal. However, their agentic attempts can be directly disrupted by parents and other adults when disclosure is forced on the basis of care and safety needs. This highlights a contradiction in different agentic needs and agendas, as well as the

generational power adults have over children (Brannen and Heptinstall, 2003; Wyness, 2015). The implications of this on the practicalities of treatment and management will be explored in the next chapter (5).

6. Summary

In summary, this chapter has explored what meanings of epilepsy children create and how parents are influential in shaping these meanings. Many children struggle to define or conceptualise verbally what epilepsy is. Instead, many spoke about what it meant for their bodies by describing the physical sensations of having a seizure or through the act of taking medication – drawing on their experiential expertise (Ironsides et al, 2003; LeFrancois, 2007). These descriptions articulated and displayed their epilepsy knowledge. For all children, epilepsy appeared to have been understood as an aspect of who they are but it is not all that they are – no child defined themselves as epileptic (Noble et al, 2017b; Schneider and Conrad, 1983). Through their understandings, many children reflected negative impressions of their epilepsy: something that scares and embarrasses children and makes them different; replicating previous studies (Benson et al, 2017; Harden et al, 2016).

Parents have been shown to hold a fundamental role in shaping children's understandings, being both a provider and withholder of epilepsy information. They are seen to assist in the development of their child's subjective understanding by providing ways for them to assemble their knowledge through their presentation of the information they have shared – such as their use of metaphors (Buchbinder, 2012; Lester, 2009). The understanding and meanings parents' themselves created also influenced what they shared, often resulting in them being selective in sharing what living with epilepsy may entail for them and their futures. This can be seen as a form of protection: parents are attempting to protect children from, perhaps, the realities of their condition (Lewis et al, 2010). Yet, in being selective, parents are restricting children's capacity and opportunities to be (more) agentic, choosing themselves the level of understanding/knowing they would like their children to acquire. Reflecting further a sense of vulnerability and (in)competency around children's illness experience as well as promoting pre-existing inter-generational power structures (Mayall, 2002; Bluebond-Langer and Korbin, 2007; Singh, 2013).

Similarly, by deferring to parents for knowledge, children reflect a view that parents hold a superior understanding of the condition as well as trusting and valuing their parents' insights and conceptualisations more than their own expertise developed through their experiences (LeFrancois, 2007; Brady et al, 2015). This notion links with ideas of adults (parents and healthcare professionals) being 'right' and seen as keepers of truth and knowledge (Mayall, 2002; see also, chapter 2). Despite this, children have demonstrated how they have absorbed epilepsy information received and agentially incorporated it into their experiential experiences to develop their own conceptualisations of the condition (Oswell, 2013). Connectedly, children's intentional ignorance around their understanding of epilepsy, indicates how they make use of their agentic capacities to shield themselves from perhaps knowing/understanding too much (Johnson, 2014). Indicating as well a sense of self-protection (Henwood et al, 2003; Wyness, 2015). This was mirrored through parents' accounts, as they spoke about moderating what information they sought independently through online resources (Nettleton and Burrows, 2003).

The control of information has been particularly pertinent in the decisions to disclose the diagnosis of epilepsy. Many children actively sought to keep their diagnosis quiet with only best, and trusted, friends being made aware and parents choosing to reveal their child's diagnosis only as a safety precaution. Through their careful control of information, both demonstrated their own insecurities of the condition: for children, being made to feel different and for parents, the risks of harm to actualise. Additionally, it illustrates an agentic quality to their disclosures, as children (and parents) decide and mediate who knows (Oswell, 2013). This also highlights the contextual situations that can encourage children to be (more or less) agentic.

Therefore, children's meanings and understandings of epilepsy are primarily derived by parents and their own thoughts and feelings of how their child should conceptualise their epilepsy. Stigmatisation around the condition is also evident at shaping the meanings and thoughts of children and parents. The material resources and inter-generational relations around information provision constrain children's agency and their opportunities to agentially engage with their condition. How children's (and parents) meanings, understandings and impressions of epilepsy interconnect with experiences of the treatment and management of the condition will be explored in the next chapter.

Chapter Five: Experiences and Involvement of Treating and Managing Epilepsy

1. Introduction

The previous chapter (4) explored how children and parents understood and assigned meaning to childhood epilepsy, this provides context through which to examine their experiences of the condition. Treating and managing epilepsy encompasses a range of different elements and processes, including medication, and seizure prevention, management, and mitigation. It is through these dimensions, that we can begin to understand how children (and their parents) experience childhood epilepsy and how it is embedded in their daily lives and routines.

As presented in chapter 1, treating and managing epilepsy are essential aspects of ensuring diagnosed children achieve a life as free of symptoms and dangers of epilepsy as possible. Medication as the main and usually first choice of treatment tool, aims to completely control and prevent seizures or at least reduce their frequency (Alcaron, 2012). Rigorous medication regimes are, however, required to ensure this best outcome is achieved, often requiring that medication be taken twice a day. While there are other treatment options (see chapter 1), medication is the only treatment discussed as it is the only treatment regimes used by the children involved. Managing epilepsy must be an adaptable process as the condition changes, but primarily focuses on three key aspects: attempting to prevent seizures; managing the uncertainty of when they could happen; and, mitigating the impacts when they do occur. The contexts within which epilepsy treatment and management processes are created and deployed can be different to each child and family. In this chapter, three particular contexts are explored: the family home, school, and the context of play and extra-curricular activities. These contexts formed the backdrop to the discussions with children and parents on their experiences of treatment and management. Chapter 7 will explore hospital-based care, focusing on the context of a routine outpatient clinic appointment and services provided by healthcare professionals.

This chapter begins with a detailed exploration of children's and parents' understandings and everyday experiences of treatment (medication), and its role in

(hopefully) preventing seizures. How children and parents seek to manage seizures will then be explored through examining how they attempt to prevent them and mitigate their impact when they do happen. Thus, how elements of treating and managing epilepsy are created, negotiated and incorporated into daily life practices and the experiences of children and parents will be explored. Additionally, how these experiences further shape how children and parents understand epilepsy, and the opportunities and restrictions of the enactment of agency that can form in the context of involvement in such practices will be examined. The following chapter (6) will draw on these findings and discuss the various roles and the involvement of children and parents in these aspects of treating and managing epilepsy, as well as examining enablers and inhibitors mediating children's agentic involvement.

2. Treatment for Epilepsy: Medication

Seizures are often described by people with epilepsy and healthcare professionals in terms of prevention and control (Schneider and Conrad, 1983; Scambler, 2004). Seizure control is achieved when seizures have been completely prevented (Schneider and Conrad, 1983; Scambler, 2004). Anti-Epileptic Drugs (AED) provides a potential means to manage epilepsy by seeking to prevent and control seizures (Appleton and Marsh, 2009). Given the vast array of seizure types and epilepsy syndromes, there are multiple medications available. This section will first explore the understandings and meanings children and parents attribute to the medication prescribed, before examining their experiences of and the challenges surrounding taking and administering the medicines. The implications this has for how children engage (agentially or otherwise) will be drawn out and further examined in the following chapter (6).

2.1. Understanding the Treatment

2.1.1 Knowledge about medication

In referring to their medication, many children described it by its preparation (e.g. liquid, tablet) or, less frequently by its colour. For example, Susanne describes the different medicines she has taken: "*the liquid one was first. Then there were the two of the tablets ones... one was a capsule tablet thing*". Similarly, Melanie describes her medication by colour: "*It's white stuff*" – representing the dense white liquid

medication she takes. When asked directly about the medication name, Wayne was unaware

Int: Do you know what the medicine is called?
Wayne: Tablet

The preparation of the medication forms the identifying and recalled feature of their medications. Other children identified their medication through the condition, calling it: "*epilepsy pills*" (Courtney and Phoebe). Consequentially, most of the children in the study did not know the name or brand of medication they took. Four children, however, did have more awareness of the name, as Craig demonstrates:

Int: Do you take some medicines?
Craig: Uh yeah. I take, like the ones in capsules
Int: Okay
Craig: I think it's Epicenta

The preparation of his medication is recalled first, and the name of his medicine is then speculated. Despite knowing its name Craig shows much more confidence in referring to the preparation of his medication. It is the tangible aspect that they are more confident in discussing, rather than demonstrating more clinically accurate knowledge and understanding of their treatment protocols.

The majority of parents could recall the name of the medication their child was taking. As Geoff, Keira's Dad, stated: "*she's on three drugs at the moment: Lamotrigine, Levetiracetam and Perampanel*". Other parents were similarly able to refer to their child's medication by name: "*Epilum, yeah it has been different forms of it and strengths but it has always been epilum for you [Alex] hasn't it?*" (Marcus, Alex's Dad). Ellen, Philip's Mum, also noted that her son was taking "*sodium valporate, though it was the liquid first but that does awful things to teeth so now it is the tablets*". Both Marcus and Ellen referred to the name of the medication but also recalled the different preparations of the medication, capturing an understanding of both the medication and its variety of preparations. Being able to recall the unusual names of medicines could be interpreted as an illustration of competency, parental engagement and responsibility for their child's treatment regime.

Despite many parents being knowledgeable on the names of their child's medication, many still frequently referred to their child's medication by its preparation: "*the tablets are all fine, just pop them out simple as*" (Marcus, Alex's Dad) and "*she takes her cocktail usually on the sofa [laughs]*" (Shirley, Abby's Mum). Referring to the preparation, not the name, of the medication can be seen to be natural for parents and children on a daily basis. This may explain the lack of information and knowledge children acquire and use regarding their medication names.

However, similarly to children, a few parents also struggled with the names of medicines, "*that one beginning with T, I am not sure?*" (Carrie, Lucas's Mum) and "*it's er... ethosuximide or something like this... a suximide one [laughs]*" (Sharon, Maisie's Mum). Neither, Carrie or Sharon were able to recall the names of their child's medicine. This emphasises that a lack of knowledge around names of medication cannot always be attributed to competency and level of engagement around treatment regimes from children. Rather, perhaps reflecting that the name of their medication is not of importance, compared with its preparation and ultimate aim (to prevent seizures).

All children were able to give some form of measurement as an indicator of their daily medication dosage. This knowledge was irrespective of their displayed understanding of medication names, and epilepsy more broadly. Less than half of children gave a detailed description of their dosage: "*it's 10mls a day, so 5 in the morning and 5 in the evening*" (Jack). Jack understands his exact dosage, in clinically relevant terms, and how it is administered across the day. Whereas, more commonly the exact dosage was reported using less clinical measurements, as Mike recalls his dosage "*I take two spoons*". Similarly, Yasmin illustrates her conceptualisation of her dosage of medicine:

Int: [...] How much medicine do you have to take?
Yasmin: 300.
Int: 300? What does that mean?
Yasmin: I don't know?
Int: That's alright, how many tablets do you have to take?
Yasmin: Three.
Int: Three?
Yasmin: Yeah. Three in the morning and three at night.

It could be assumed that Yasmin takes three individual 100mg dosage tablets in the morning and the same again in the evening. Each child's understanding of their dosage can be seen to form around how their dosage is discussed more broadly in

everyday life, just as their knowledge around medication names developed. This understanding could also be illustrative of how children choose to conceptualise their medication in terms of its preparation and how it is administered to them; Mike, for example, has his medication administered on a spoon. Of note, the more accurate or clinically correct responses were seen in children that had a better understanding of epilepsy, which connects to the previous chapter (4). Nevertheless, it was not an indicator of how involved or engaged the child was with their treatment regimes, as will be demonstrated in the next chapter (6).

For most parents, the dosage was often provided with relative ease and spoken about naturally. Susanne's Mum, Jane responded "*epilum 100mgs*" straightaway when asked what medication Susanne was on. Similarly, Monica, Courtney's Mum, recalled: "*Well she takes 1000mg of Keppra twice a day*". The dosage is ingrained in their responses and the way they speak about medication in general. This manner is similar to how parents and healthcare professionals spoke about medications during observed clinic appointments, suggesting clinical settings generate a vocabulary and approach to discussing medicines parents have adopted (see chapter 7). Other parents were less precise in their discussions of medication dosages, noting instead the number of tablets or syringes worth of medication that must be taken: "*he has two tablets*" (Carrie, Lucas's Mum). Irrespective of how the measurement was conceptualised, all of the children and parents knew the dosage of medicines they must respectively take and administer.

Three children expressed curiosity regarding their medicines. As I spoke to Phoebe about her medication, she added, "*There's one that's yellow and you can see through it and I've always wondered about that one and what medicines have in it*". The appearance of the medication has caused Phoebe to question what it contains, perhaps seeking a more detailed understanding of her medication and exactly what it is composed of. This curiosity could highlight children's pursuits for different degrees of understanding and explanations of their treatments.

2.1.2 The role of medication

Most children knew why they were taking medication, what the desired effects were and the relative importance of taking the medication. The majority of children spoke

about their medication in terms of this effect: "*it stops my headaches*" (Rosie) and "*they are stopping me having seizures*" (Esther). These children explained their medication through its impact on their seizures, or rather their lack of seizures. Indeed, the idea of medication being able to '*stop*' seizures was a common theme in most of the children's accounts. Even in the context of continued seizures, two children (Keira and Wayne) also spoke with certainty about their medication as being able to stop their seizures. When asked why she continued to take medication every day, Keira responded: "*it [medication] does stop the fits*". Similarly, for Wayne:

Int: *Why do you have to take these medicines?*
Wayne: *Cause my brain fizzes if I don't take them.*

They both have regular '*fits*' and '*brain fizzes*' according to their own accounts. Yet their belief in the power of medication as a treatment tool is unfazed by their continuation of seizures. Their account highlights the strong belief among the children in the therapeutic power of medicines.

This idea of medication '*stopping*' seizures was also evident in the children's response to Ben's story, one of the three comic book vignettes used during the first interview to encourage discussion around common issues associated with treating childhood epilepsy. Many children linked the importance of medication to the consequences of Ben refusing to take them. For example, when asked what she would say to Ben given his situation, Rosie suggested:

Int: *So, what would you say to Ben if you could say something to him about what is happening?*
Rosie: *I'll say, 'Ben you need to take your medicine or you'll get a sore head'.*

Rosie's perspective on the importance of medication is inextricably linked to the consequences of not taking medication: for Rosie, getting a '*sore head*' reflected having a seizure. The children emphasised with certainty the imperative that Ben take his medication "*Well he really needs to take his medicine*" (Courtney) and "*he has to though*" (Lily). This understanding of Ben's situation further stresses that children view medication as of central importance in managing their epilepsy.

Nevertheless, among some of the children there was also a sense that the 'stopping' of seizures may only be a temporary pause. The medication has stopped seizures, for now. As Emma reflected: "*they were saying you can take the medicine and then it might help, might stop you from having... it might help stop some of them [seizures].*" Emma explained the medicine '*might*' help stop '*some of*' her seizures, indicating less certainty in the belief of medication's therapeutic power and whether her seizures will reappear or not. This sense of uncertainty was present even when seizures have been prevented for a while. For example, Jack had been seizure-free for nearly two years at this point, yet still spoke about his continued use of medication:

Jack: But I had I had, I knew I had to take it
Int: Why did you know you had to take it?
Jack: Well at that time we weren't sure when if the epilepsy could come back on so yeah.

Jack's uncertainty around the potential for his '*epilepsy to come back*' was coupled with his absolute certainty that he '*had to*' continue taking his medication.

The experience of taking medication was however not just for children, with the significance of adults (parents and healthcare professionals) clear in shaping children's experiences and understandings of their medication as highlighted through Jack's references to '*we*' and Emma's references to '*they*' in their reflections above. It is through discussions with others that Emma, for example, develops her understanding of the complexities and uncertainties of her medicine, and Jack's shared feelings that '*they*' could not be sure whether his seizures would return. This also reflects the broader observation of their epilepsy being considered a joint and shared project with children and their parents.

Only a few parents explicitly discussed medication as a treatment to prevent seizures. Yet, in contrast to children's accounts, these few parents only focused on medication as a *failure* to treat their child's seizures and not as being able to stop them. As Geoff, Keira's Dad, recounts, "*we don't know if the drugs are having much impact on her seizures even at low dosage*". The purpose of medication is spoken about in terms of its failings: it does not seem to be preventing Keira's seizures. This reveals a great sense of uncertainty around the medication.

Additionally, many of the parents spoke about how to explain to Ben why taking medication was important by connecting it to potential consequences: "*Well somehow you're going to have to cajole him to see why it's important to take this*" (Verity, Esther's Mum). Craig's Mum, Annie expands: "*maybe it comes back to them [Ben's parents] needing to sit Ben down and chat over why he needs to take them and what the consequences are if he doesn't...*". For Annie, Ben needs to understand the importance of the medication and the implications of him not taking it, making clear the consequences. Annie also stresses the role Ben's parents have in providing such explanations, illustrating the shared role of treating epilepsy and their role in shaping children's understandings of and involvement in their condition and its treatments.

Furthermore, most parents, however, rarely spoke explicitly about the role of medications in preventing seizures. Instead, this vital role of medication was an implicit feature of many of their discussions. For example, Katherine, Peter's Mum, remarked, "*He's [Peter's] had nothing since we've been on meds*". Katherine views the medicines as having its desired effect: it is preventing Peter from having seizures. This lack of discussion from parents could be because for them medication can be seen to be successful; medication has controlled and prevented their child's seizures. However, there was also a sense of trepidation in Katherine's reflection as to whether seizures will return – there has been '*nothing since the meds*'.

Wendy, Mike's Mum, explores this sense of nervousness of the continued success of medication further:

they [doctors] tried to wean him off again and he was fine and then they [absence seizures] came back and he had one falling down one [tonic clonic seizure], and so they just put him back on [medication] again. But that was our third time lucky, didn't work [laugh].

Healthcare professionals have sought to wean Mike off his medication repeatedly according to his Mum, Wendy. This process tends to occur when a child has been free of seizures for two years to ensure that a child is not being unduly medicated (Appleton and Marsh, 2009). However, it appears that Mike's seizures are prevented only when he is actively taking medication, when he stops taking it, his seizures return. This creates uncertainty around complete seizure prevention for Wendy and produces an increasing reliance on medication to provide a successful treatment. Both Wendy

(Mike's Mum) and Katherine (Peter's Mum) indicate implicitly the importance of the medication in preventing seizures, but also illustrate an apprehension of its continued effectiveness as a preventative treatment against their child's seizures.

The meanings children ascribe and their understanding of the role of medication is drawn from the tangible aspect of their medicine, how they discuss it with their parents and the outcomes they directly experience (e.g. seizures stopping). This means the acquiring of new and often technical knowledge and ascribing meaning which is unsurprising given how children's understanding of epilepsy is developed (chapter 4), and replicates previous studies (e.g. Bozoni et al, 2006). How this knowledge and understanding influences children's wider experiences of their treatment and management is explored over this chapter and the implications it has for their involvement will be further explored in the following chapter (6). The next section examines the experience of taking medication.

2.2. Experience of Treatment

The role of medicines in preventing seizures has shown to be well grasped by children and parents, yet to give the best chance for anti-epilepsy medication to be successful in preventing seizures, it is recommended that a complete prescribed dose should be taken as directed. Taking medicines daily can be an adjustment for children and their parents. This section will explore how the treatment regimes are incorporated into children's and parents' lives.

2.2.1. Taking Medication

The format or type of children's anti-epilepsy medicine (AEM) was the central element of children's experiences of taking (or not) their medication. The physical composition and format, or the preparation, of AEMs available varies considerably depending on the medication prescribed, including liquid, tablets, chew tablets etc. In discussing taking their medicines, all children described the size, texture, and taste of their medicines and how these aspects coloured their experiences of taking them.

Lucas, for example, reflected on his experiences of his tablets: "*they are big and horrible. I can choke*". Lucas finds the size and presumably taste of his tablets

troublesome. This can be compared with Esther, who spoke about taking her chewable tablets:

I either chew them or when I try to swallow them they sort of disintegrate in my mouth and I run the tap for ages just to get some water and now they've disintegrated on my tongue [laugh]!

The texture of Esther's tablet changes as they break down quickly in her mouth. The size and texture of Esther's and Lucas's medicines taints their experience of taking their medicines, creating potential negative associations. Other children however had less challenges with their medicines: "*It's just a small one... I swallow it whole*" (David), "*they're super small and ok to take, the purple one is big though*" (Iain), and "*just spoon in mouth and gulp*" (Mike). The smaller tablets and liquid medicine appears to make these children's experiences of taking their medicine less unpleasant and their reflections demonstrate less challenge with taking them.

For other children, it was more the taste of the medication that influenced their experiences. Iain also recounts taking his medicines: "*I don't really like it, I don't really like tasting it*". Also, Alex felt that the reason Ben, from the first comic book vignette, did not take his medication was due to the taste: "*Cause he doesn't like the taste*". This was not a universal issue however; a few children reflected that their medication did not really taste of anything: "*they taste of nothingness*" (Philip) and "*They just taste like plain*" (Alex). The difference in opinions illustrates the variety of individual differences amongst children's reflections and experiences of taking medications.

Negative associations with taking medication were also reported by a few parents. Wayne's Mum, Robyn describes: "*it was quite stressful cause he was gagging and things cause it's quite a big tablet, it's pretty big...*". Wayne struggling to swallow his medication due to the size of the tablet is distressing for his Mum, creating a difficult situation for both of them to experience. This also further illustrates the shared experience of medication taking and treatment regimes.

The creation of negative associations from the size, texture, and taste can cause medication taking to be challenging, making the process unpleasant, distressing, with implications for following medication regimes. Despite this, most children took their medicines easily – accepting and putting up with the negative experiences. A handful

of children reflected on how they had become used to taking medication: " *Yeah, the first time I really didn't like it, I was like 'that was rank!' but I've got used to it now*" (Peter). Similarly, David discussed the difference between the first time he took medication and now:

David: First time... I just trying to swallow it but I coughed it back up.
Int: Oh, dear. Does that always happen?
David: No I got used to it.

Peter and David were both able to 'get used to' taking medications. This acceptance of taking medication, despite the initial and sometimes persistent issues, is significant, should medication become a successful and reliable part of the child's treatment regimes.

Similarly, when asked how they found taking their medication, many children simply stated: " *Er, it's fine*" (David) or " *just normal*" (Yasmin) with minimal reflection. Mike offered a bit more insight: " *It's just like juice or something*". These insights could be interpreted as another example of how most children have become used to taking medication, viewing it as just something that must be done, a normal, unobtrusive necessity. Many parents' accounts also reflected such a 'getting on with it' attitude. Craig's parents spoke about Craig's taking of medication:

Lee: he has never said that his medicines are yummy [laugh] or even that he particularly likes them, but he doesn't say no I don't want to, he just gets on with it-
Annie: -He just gets on with it.
Lee: Yep. Just gets on with it.

A few other parents spoke about challenges and frustrations when their child first began their medications. Mike's parents, Wendy and Don, reflected on administering the first liquid medication Mike was prescribed:

Wendy: The minute he saw that coming he refused to take anything, so you actually had to kinda force it down.
Don: We'd to pin you down [directed to Mike, laugh]! Almost though, just we were making sure it was going in, he used to spit it out and stuff like that.

Coupled with the frustration of Mike refusing the medication is the grave sense of responsibility his parents felt about ensuring he took all of his medication. Holding Mike down reveals the level of struggle that his parents faced as well as the extent to which he simply did not want to take his medication. This reveals a tension between moral parenting imperatives and a need for their child to take the medication, as well as generational power imbalances. Don went on to explain:

But now taking the medicine it's absolutely not, it's not even a problem, he can be sitting watching the telly and you'll go up just put the syringe next to him, he'll just turn round, take it and that's it.

Problems may have arisen in the past but they are now long gone, taking medication has become a non-issue for Mike and his Dad.

In order to take their medication, a handful of children spoke about strategies that they had developed to counter the negative aspects of their medication. Nicola spoke about her strategy:

Int: So how do you take it then?

Nicola: I just do it fast.

Int: Fast, oh wow.

Nicola: Yeah, I used to take water too but now it just tastes worse when I try to do it.

Nicola's reflects how she has changed the way she takes her medication to mitigate the bad taste it creates. This connection with avoiding drinks afterwards was seen in two other children's strategies to taking medication. Other strategies children developed included taking medication quickly and trying not to chew the tablet as they swallowed it. These children have developed their own agentic strategies to cope with the negative aspects of their medication, making their experiences more palatable. Although these children have found strategies that have worked, this is not always the situation and some children struggle with taking their medication.

For four children, medication taking remained a considerable issue. For Maisie and her Mum the challenges around Maisie's medication taking were discussed in great depth throughout both of their accounts. Maisie reflected on her struggles with taking medication and the strategies she had tried:

- Int: What's it like taking it [medication]? [Maisie shakes head] that bad?*
- Maisie: Yeah sometimes I hide or I just don't like taking them because... it depends what we eat. Because when you eat you can get that flavour in your mouth and that just, I don't know. It just doesn't work sometimes.... But sometimes when I have been taking the medicines I haven't been eating enough food and I have been sick. So that's really what, why I don't want to take it because I don't like being sick.*
- Int: Oh dear, so you don't like taking the medicines?*
- Maisie: Uh-huh. It's because I have [to] eat a lot before or else I get a sore tummy.*

Maisie has resorted to hiding or refusing to take her medicine because of how it makes her feel afterwards. She has been unable to find a strategy or solution to help her take her medication, she would just rather not take it; indicating parents own struggles. A discussion of medication side effects will be presented later in this section.

Sharon, Maisie's Mum, also spoke about Maisie's reluctance and refusals to take her medication from her own perspective:

...trying to get her to take the medication, it's hard. I mean you can fight with her for an hour in the morning and eventually you have to give up as you gotta get her to school. That's probably the hardest erm is trying to get her to take the medication [...] in the night there is no problem at night as she got in her head that the medication makes her sick. Which is a side effect. So she's got to have her breakfast in the morning before she can take her tablets, yet she's doesn't eat in the morning so this is where... She refuses to eat and then she refuses to take the medicine because she's not eating. [...] then she'll be or feel sick. It just goes in circles. Night time is fine. There has never really been an issue with taking it at night time, annoying as we never have the time for the argument but in the morning she's... there is always an argument.

There is a mutual sense of frustration around the medication taking for Maisie and her Mum (Sharon), illustrating the complexity and challenge involved in taking and administering medication on a daily basis. Interestingly, the argument seems to take place regarding only the morning dosage, from Sharon's perspective. With this, Sharon suggests that Maisie's problems with her medication goes beyond the taste and her feelings of being sick, perhaps hiding a bigger problem with medication than Maisie would like to share.

Maisie and her Mum are not alone in these feelings around taking medication. When asking Abby about her medicines, she simply stated: "*hate taking it*". When I probed

why, Abby responded: "*I just want to, you know, I just want to... don't take it*". There was no other reason to add, medication was not something Abby wanted to be taking. In discussing Abby's medication taking, her Mum, Shirley, felt that although Abby takes her medication relatively well, "*she's a bit like why do I have to keep taking it*". These insights reflect Abby's unhappiness to take medication, reflecting perhaps a sense of powerlessness to refuse; the generational power imbalances restricting her agentic actions. This could also possibly demonstrate her lack of understanding of why she has to continue taking it.

Parents also created strategies and ways of managing their child's medication when they were aware of the challenges. When I arrived to interview Abby and her Mum (Shirley) at their home it was before Abby took her morning medication. Abby's medicine was comprised of two dispersible tablets and a liquid, these were mixed together with a little water and some squash. The concoction was served in a rather fancy glass adorned with a small paper umbrella, like a cocktail. Shirley later mentioned during her interview that, "*with a cherry on top and a wee umbrella will make her [Abby] happier!*" Shirley's strategy turned taking medicine into something special that could be potentially enjoyed as well as being practically easier for Abby to take. This illustrates the strategies parents can, and do, adopt to ensure medication is taken, actively seeking solutions and compromise that does not inhibit the treatment regime.

The challenges around medication taking are not just for children and parents; rather, other family members can become entangled in the process. Jane, Susanne's Mum, for example, recalled a particular family holiday:

Jane: oh I remember being away, we'd gone to [holiday destination]-
Susanne: -not this story [muttered]-
Jane: -as a long weekend and I remember her screaming-
[Susanne's] Sister: -it was terrible!-
Jane: -the room down. Trying to get her to take her medicine before we went anywhere. It was awful.
Int: oh dear
Jane: it was quite bad. I think now what we've been through... glad it is not like that.

The family holiday was on hold until Susanne's medicines were taken. The interjections from Susanne's sister emphasises how the whole family has become involved in the process of administering medication, including sharing the frustrations associated to it. Although there is an element of shared experiences between children, parents and wider family around taking medicines, it is only the children who directly experience the medicine. Nicola's reflection on the taste of her medicine illustrates this unique experience:

Nicola: It tastes of bananas and vinegar.
All: [Laughter]
Shona: -Does it?
Nicola: Yeah.

Nicola's Mum, Shona's interjection shows her surprise at Nicola's description of the taste of her medication. Parents will often not know the true flavour or texture of medication, as they are not the one taking it. This lack of direct experience can cause issue when taking medication is not a pleasant activity. Children must overcome such challenges and negative aspects by themselves. As Marcus, Alex's Dad, added: "*many times I'd say 'you're taking it and if it's terrible, tough, it's going to help you'* [laugh]". In these cases, the importance of the medication are seen by parents to override their child's experience of taking the medicine. This can potentially result in children having to develop their own strategies by themselves to cope with the negative associations of ingesting their medication.

However, this was not the case for four parents. When Lily refused to take a previous medication due to the taste, Christine (Lily's Mum), tasted it:

it's disgusting, I've tasted it cause I thought 'right if mummy can take it, she can take it' kinda thing, but it was absolutely disgusting. I hate to think that children were actually on that medicine.

By obtaining this insight into the taste of the medicine, Christine has realised how horrible it must be for Lily to have to take it twice a day. As a result, she spoke to the doctor and managed to change the medicine to a better tasting one. Illustrating Christine's role as an advocate for her daughter with healthcare professionals. Christine was the only parent to report tasting their child's medicine.

Similar to Christine, the three other parents spoke about actively switching the preparation or type of medicine to attempt to make it easier for their child to take. Susanne's Mum, Jane recalls all of the medication changes they have gone through:

erm... well... the first one she had was a liquid...medicine... which she just couldn't take, it would make her ... sick... [...] And then we... got... another medicine which again was just as bad and she wouldn't take it either. Then we got a tablet form... which you could take as long as you crushed them. Then we got the one now.

The perseverance of Jane's attempts at finding a medication that Susanne can take without trouble is clear, demonstrating her advocating for her daughter. No other parents discussed such an advocacy role for their child in connection with medication taking. The option of trying different types and preparations of medicines was, though, suggested by just over half of children when discussing Ben's story and what could help him take his medications.

2.2.2. Routines of Medication

The repetitive nature of children's and parents' experiences of taking and administering medications respectively was intrinsic to their accounts. Most reflected on this repetitive nature by explaining their medicine dosage and cycle of treatment through their routine and habits: "*It's one at breakfast and one at dinner*" (Wayne), "*I take it at eight o'clock in the morning and eight o'clock at night*" (Peter) and "*it's one big one in the morning. A big one and a small one at night*" (Craig). Parents spoke about administering their child's medication in similar, routinised ways: "*first thing in the morning when she takes the rest of her pills she takes that and then at bedtime*" (Monica, Courtney's Mum) and "*6mls twice a day, so 6mls in the morning and 6mls before he goes to his bed*" (Wendy, Mike's Mum). The taking of medication has become embedded in daily life with predictable times for it to be taken.

These timings became incorporated with meal times, as Jane, Susanne's Mum, described: "*What I tend to do is when we are setting the table, her tablets get put beside her and straight after the meal, they get taken*". These patterns of experiencing the taking and administering of medicines provides insights in to how parents and children incorporate the treatment regime in to their daily lives. It moreover illustrates how children and parents conceptualise and understand their medication in terms of

their routines and the everyday. As Shona, Nicola's Mum casually explains: "*it's part of her routine*".

The habitual nature of taking medications can become so ingrained in the routine of daily life that it can be quickly forgotten. For example, Shona (Nicola's Mum) added:

I think probably to the point where if I was to say to her half an hour after giving it to her, if I was to say 'have I given you your medicine?' she'd be like 'eh... don't know?' Because it's just... it's very quick, she takes it and that's it.

The habitual nature of taking medication means that there is minimal (or no) engagement or reflection on the process from Nicola. This could perhaps give the impression to parents that children are not engaged in their medication, which can have implications when discussing agency and capacity for responsibility. This will be explored further in the next chapter (6).

Having a routine did not always ensure that medicine was remembered all of the time. Around half of children and parents recalled a time or occasion when medication was forgotten, as Iain explained: "*One morning I forgot to do it with Mum and then Mum forgot to do it to me*". Forgetting to take medication can be linked to a change of routine, for example, Ryan, Emma's Dad, recalled, "*Tuesday night we left the house to go to [location] for tea, halfway down the road 'oh we've forgotten the medicine' so we had [Son] running back for it [laugh]*". The going out for dinner has thrown Emma's family routine for medication administering, causing medicines to be forgotten. For Emma's family, this appears to be a simple mistake, which they have laughed off. This is not always the case, as Jean, Iain's Mum, reflected on forgetting Iain's medication one morning: "*it was the most important thing and I felt the worst Mum in the world and kept thinking 'he's going to have a shake today because of me'*". Jean expressed a huge sense of personal failure as a parent, as it was her responsibility to administer the medication. This sense of perceived parental responsibility enacted through the administering of medication is seen throughout parents' accounts.

In sum, children illustrated their capacity for agency through developing their own strategies around taking medication, often without their parents fully appreciating the scale of the negative experiences (Oswell, 2013). Children and parents' experiences of medication and the connected regimes demonstrates a shared dimension to

treatment. Some parents' also created strategies to make medication more palatable and to fulfil the *need* for their child to take their medication, ensuring that medication was as palatable as possible. In doing so, they positioned themselves as advocates for their child. However, when such strategies did not work or when children refused, tensions emerged with parents' moral imperatives (and responsibilities) and the need for children to take medication (Niedel et al, 2013; Wyness, 2015). The generational power imbalances also further compounded children's agentic attempts (Mayall, 2015). Changes to treatment and how this is experienced by children and parents will now be explored.

2.3. Changes to Treatment

Although routines are created around the administering and taking of medicine, medication as a treatment tool is not always static, particularly when unsuccessful at preventing seizures. Where seizures continue dosages can be increased or the type of medication completely changed. Each change to medication can alter the experience of taking and administering it as well as having emotional implications for children and parents that follow an unsuccessful treatment. It is these changes and the associated implications that will now be examined.

All of the children in the study have experienced some degree of change to their medication since diagnosis. At the time of their interviews, four children's medicines were proving unsuccessful, seizures were still occurring despite their medication regime. Whereas others had found a medication and dosage that worked for them (at present) to prevent their seizures. Seventeen children have changed their medication type at least once since diagnosis and all children have had their dosage increased at some point (see table four). Given these changes, children and parents are experienced in the process of increasing and altering medications.

The majority of children spoke about the variety of medications they had been prescribed by comparing the different textures, tastes, and preparations of their various medications. There was very limited, if any, discussion from children on what having different medications meant to them, their epilepsy, or what it meant to increase their dosage. This could perhaps reflect the 'controlled' nature of the sample; most of children were on stable doses that controlled their seizures. There were two

examples where children reflected on the meaning of medication changes to some extent. After explaining how previously she had taken eight tablets a day for her epilepsy, Phoebe added it was "*because I got it really serious back then*". Phoebe makes a connection between the number of tablets (or dosage) with the severity, or seriousness, of her epilepsy.

Nicola, who has changed medication type three times with little long-term success, was the only child to offer insight into why she had to switch medicines, stating, "*they said that it wasn't working properly*". Nicola has been told that her medication is not working. She does not however appear to recognise their failing, herself. When I asked Nicola what it meant to 'not work properly', she simply shrugged. There was nothing more to be said about her medicines, she has accepted the change of medicines again. There was no further reflection on the process of changing medicine and what this could mean for her or her condition.

In contrast to children's accounts, parents' accounts were littered with reflections on what changing medications and increasing dosages meant for them and their children. Such insights were particularly apparent in discussions around changing medications. Charlotte, Phoebe's Mum, reflected on the numerous times medications changed:

you hope that it's going to work but it takes a very long time for the medicines, you know, to actually get working and then hopefully you're not going to have the side effects which we've had for quite a few, we've been on and off quite a lot and it just takes months to get there and if it doesn't work you have to come off it again and it takes a while to come off the drug and then you start a new one and you just think...

Charlotte's hope that the medication will work is heavily tempered by time: the time it takes for the medication to take effect, and the time it takes to come off the medication when it does not work. The notion of time is further complicated by the concern of potential side effects from the medication. The combination of all these elements heavily influences how the medication as a treatment is conceptualised by parents and the uncertainty that surrounds it. Furthermore, the reflection of '*we've been*' and '*we've had*' further exemplifies the shared experience of treatment with her daughter: Charlotte is experiencing every aspect of the treatment failing and changing as much as her daughter.

John, Nicola's Dad, mirrors many of these sentiments: "*I guess it's just a case of hoping that we will finally get her on the right medicine eventually, it's sad there is no quick fix, it's just trial and error with these medicines*". The hope, the uncertainty and the time it takes to find a medication that prevents Nicola's seizures is evident in John's reflection, particularly with regard to the treatment being '*trial and error*'. Additionally, the reference to '*we*' in terms of finding a new medicine that works illustrates a sense of responsibility that parents can feel in connection with the treatment and its hoped success. Both Charlotte (Phoebe's Mum) and John (Nicola's Dad) experiences also demonstrate how complex childhood epilepsy can be to treat effectively and the effect changing treatment regimes can have on parents.

Unlike changing medicines, all children experienced the increasing of their medication dosage at some point. Increasing of dosages usually occurred when a child continues to have seizures and are not at the maximum recommended dose. But to ensure that the medication remains at the lowest dosage to give therapeutic benefit, the dosage must be increased slowly. A handful of parents reflected on these subtle changes to the treatment regime and what it meant to them. Shirley, Abby's Mum, spoke about finding the right dosage for Abby:

It was quite stressful thinking about increasing medication all the time, because each time she took a seizure we had to increase the dosage. So she had to take one more tablet or whatever erm and I just kept thinking when is this going to level out, I mean we knew that we couldn't increase it [medication] any quicker [...] it was a bit stressful, like oh no how many more tablets can she take you know.

Shirley's concern and anxiety about the potential success of the medication is seen alongside the hope of whether this next increase would reach the perfect therapeutic level to prevent Abby's seizure. The role of the medication as a treatment tool is being questioned by Shirley as well as the potential 'other' effects the tablets could be having, suggesting there is a limit to what Abby could take. The repetition of '*we*' throughout further supports the shared experiences of treatment and the condition more generally.

As illustrated, there is minimal reflection on treatment changes and increases to medicines by children, revealing perhaps the lack of insight they are exposed to (by their parents and or healthcare professionals) and or their desire to engage regarding

their treatment protocols (Brady et al, 2015). Both have potential implications for children's agentic opportunities and involvement in their treatment. For parents, more so than children, changing medications and increasing dosages can bring forth uncertainty and anxiety around seizures stopping. This led to parents questioning the efficacy and ultimate success of the treatment. Parents continue to hold hope for a medication to work to prevent their child's seizures, but this hope is very much mediated by the uncertainty of whether it will be successful (Webster, 2017). The experiences of treatment side effects will now be explored.

2.4. Treatment Side Effects

When choosing which medication to start or when exploring whether to change medications, one factor that can be greatly influential is the known, experienced or potential side effects. There is a range of known side effects to anti-epileptic medications (AEMs), from minor issues to more substantial and significant impacts, varying from person to person. It is important to balance the effects and the impact they can have on a child's wider health and life with the medications aim to prevent their seizures.

This balance between side effects and intended effects of medication is delicate, as Verity, Esther's Mum contemplated: *"a lot of kids will have side effects but it's a real balancing act"*. Verity suggests that tolerating some side effects are almost required to ensure seizure freedom. Finding the balance between side effects and having the intended effect can be challenging. Six children and fifteen parents spoke about side effects in terms of toleration. For example, Emma states, *"I don't mind the tiredness... I want the medicine cause I don't like seizures, they're not nice"*. A balance, in some respect, has been achieved; the side effects are accepted when compared to the potential consequences of seizure.

The side effects discussed by the six children were primarily negative. Craig, for example, spoke about a previous medication he had been on: *"And that one it sorta made me bad because like I just wasn't acting the same. I went more grumpy and, like, had more fallouts with my Mum"*. Similarly, Phoebe spoke at great length about previous medications and their effects: *"I was taking bad medicine and it made me sick. It was making me really sick and making me have bad emotions and stuff"*. Both

Craig and Phoebe have made overt connections with changes in their bodies, behaviours and moods with their medication: it was the medicines making them 'bad', not them. For Phoebe and Craig, the balance between manageable side effects and seizure freedom was not achieved. They both changed their medications because of these side effects. In contrast, Mike spoke about a positive side effect of his medication: "*when I go to bed it usually relaxes my brain*". Mike's thoughts on his medicines' alternative effects were nevertheless unique.

Most children, however, made no mention of side effects of their medication. This may not be something that children are experiencing or the effects they experience could be minor and unworthy of reflection. Yet, the majority of children did acknowledge that Ben was experiencing the side effect of tiredness when discussing his story from the comic book vignettes: "*those [indicates the medicine in the picture] make him tired*" (Lucas) and "*it's his medicine that is doing that [...] making him grumpy*" (Alex). This illustrates a minimal degree of understanding of side effects and alternative impacts of taking medication from children.

Some parents reported that children's lack of awareness of potential side effects could be seen as a mixed blessing. Geoff, Keira's Dad, reflected as he spoke about Keira's side effects:

irritability and insomnia, but she hasn't associated them with the drugs [...] I don't know, I mean, if... I suppose if the drugs are causing the problems and she knew that then maybe she wouldn't take them... but maybe it would be useful information for her.

Geoff knows that Keira has side effects from her medication but is torn as to whether making her aware of these effects would be constructive. Additionally, he is deciding that the balance of effects is tolerable for Keira – leaving very little room for her to contribute to this decision. The almost withholding of this information further illustrates how much of children's informational understanding of their treatment is obtained from and, vitally is mediated by their parents.

In contrast to the children's accounts, side effects of medication featured prominently in the parents' accounts. For example, Derek, Iain's Dad, explains:

The medication's certainly taken a wee spark from him. He used to be... on the football park he was fit as a fiddle, now you can see he's just lethargic and he's just not as quick and bright. He's fine mentally but physically he's not the fittest boy.

Derek reveals a sense of mourning and sadness for what Iain could do and how he appeared before the medication took his 'spark'. Nevertheless, the medication was continued. Charlotte, Phoebe's Mum, spoke about a similar loss when Phoebe took one particular medication:

it really changed Phoebe's personality, the side effects were she was very tired all the time and she just wasn't quite herself, and so having coming off this medicine I'm really seeing Phoebe back to her character again which is good

There is a sense of relief in Charlotte's reflections that is missing from Derek's (Iain's Dad) reflection. Charlotte found that the side effects of the medication disappeared and Phoebe's old personality re-emerged as she changed medications. There is a noticeable impact and effect of the medication, which can be seen as distinct and separate from its role as a treatment. This colours and influences parents' experiences of the treatment.

It was these potential and known side effects that initially made Colleen, David's Mum, very reluctant to start David on medication for his epilepsy. She reflected: "*I'd seen all the side effects that can be thrown at you with medication and I was just... I was so reluctant*". Colleen went on to explain that it was only David's own insistence and her wish for his seizures to stop that outweighed this reluctance that he started medication.

As demonstrated, children did not focus on potential side effects of their medication; following findings from the previous section on changes to their medication, and replicates prior research (Webster, 2016). Whether this lack of reflection was due to them being unaware of the effects or not is less clear, as most children demonstrated an understanding of potential side effects through their discussions of Ben's story. Parents' accounts showed worry and concern of side effects (Webster, 2017). How parents mediate information around side effects further illustrates how parents are influential in the development of children's understandings and the influence this has

on their enactment of agency, reflecting previous discussions (Brannen and Moss, 2003; Brady et al, 2014).

2.5. Summary

The taking of medications as a treatment for preventing seizures (and more broadly for epilepsy) is seen to be complex, yet heavily incorporated into routines of daily life for children and parents forming a shared activity. Children's level of understanding and knowledge of their medication ranged in depth and breadth; it appeared dependent on how parents and others discuss medication implicitly and explicitly with them (Bozoni et al, 2006). While there are gaps in children's knowledge and understanding it has been suggested that this is more than adequate in the context of their everyday life. Moreover, children's conceptualisations must be balanced and understood in its context and not seen as a deficiency in awareness or competency but more as an appreciation of how they have chosen to understand their medication (Brady et al, 2014). Children's knowledge and understanding and their exposure to new knowledge and ways of understanding influences a child's opportunity to develop and refine their agentic capabilities (Christensen et al, 1998).

The challenges of physically taking medicines daily and the potentially isolating experience this can be for children has been shown. Alongside this, children's agentic strategies to facilitate their medication taking was evident in both demonstrating their agentic capacity and consideration of the consequences (Christensen et al, 1998). These strategies children developed were not necessarily recognised by all parents, however. Children frequently reflected the shared nature of their treatment regimes. Some parents actively sought to appreciate and support the taking of medication by making the process as acceptable as possible. Yet, for many parents, the overriding need for their child to take the medication was central; ultimately, all parents saw adhering to the medication regime as being a parental responsibility (Churchill, 2011; Neidel et al, 2013). This overriding *need* could, however, overshadow or restrict children's attempts at agentic action in refusing to adhere to regimes (Singh, 2013; Bluebond-Langer and Korbin, 2007).

Children and parents shared an understanding of the importance of the medication in preventing seizures. Changing medication was however seen by parents as a failure

of treatment and led to concerns of uncertainty for future success. Children were less attuned to such changes in their medications, treatment regimes, and side effects, appearing disengaged, or unaware, of them. This lack of understanding could be attributed to the information and insights parents revealed to their children (Wyness, 2015). The consequences of this on involvement and agentic opportunity will be discussed in the following chapter (6); the next section will explore experiences of managing epilepsy.

3. Managing Epilepsy

Treatment is only one aspect of epilepsy, managing potential seizures and mitigating their impact when they happen is also central to the experience of living with epilepsy. Seizures can happen unexpectedly and can put children at a greater risk of accidents and or injury when they do occur (Moffat et al, 2009). Given the increase risk of harm, healthcare professionals and epilepsy advocacy charities frequently provide safety advice and discuss levels of risk with regards to potential seizure activity (Epilepsy Action, 2018). This section will explore how children and parents manage epilepsy, addressing the prevention of future seizures and mitigating the impact when seizures occur.

3.1. Preventing Seizures

For the majority of children, there are no warnings that a seizure could happen. This caused great uncertainty around seizures occurring and was common across many children's and parents accounts. Despite this, understanding and knowing potential activities or situations that can cause seizures can be one way to prevent seizures from occurring. For example, rapidly flashing lights is known to trigger epilepsy in those who are photosensitive (Alcaron, 2012). Five children discussed potential or known triggers for their seizures. For example, Nicola mentioned: "*if there's lots of noise they happen*" linking noise to her seizures occurring. Only eight parents reflected on potential triggers for their child's seizures. Tiredness and a lack of sleep were seen as the most common triggers: "[Phoebe] *would have more absences when she was tired. Definitely*" (Phoebe's Mum, Charlotte), and similarly being busy was also seen as a trigger: "*it always comes after he's either been out and about the whole weekend, busy doing things*" (Wayne's Mum, Robyn). Another common trigger was illness: "*When he gets sick, they happen*" (Marcus, Alex's Dad) and *she tended to get them if*

she wasn't well [...] so every time her immunity dropped it seemed that she just kinda had them as well, which was a bit strange." (Sue, Rosie Mum). Even though the detail of the connection is perhaps not understood by Sue, Rosie's Mum, there is the known understanding that when Rosie is unwell, her seizures occur.

Three of the parents who spoke about triggers were less certain that there was a specific, or set of, triggers that could be causing seizures, as Craig's parents discussed:

Annie: *well we've not really found a trigger for him at all.*
Lee: *when he gets tired I suppose?*
Annie: *yeah tiredness could be it, though we could have worked that up to be honest*

The speculation around potential triggers is seen, there is no certainty on Craig's triggers. Annie, Craig's Mum, is even querying whether they have made it up rather than it being based on a particular evidence base. Other speculations parents mentioned included, watching TV at night (Verity, Esther's Mum) and playing on a gaming console too much (Colleen, David's Mum). The minimal awareness and certainty of triggers to seizures, in both children and parents accounts, illustrates the vast uncertainty around when seizures could happen as well as the complexity of childhood epilepsy and its treatment and management.

Most parents and half of children reflected on Louise's story, from the comic book vignettes, with reference to seizure triggers. Many suggested that Louise's seizures were being triggered by her lack of sleep. For example, "[Louise] *should go to sleep, cause she can have seizures without going to sleep*" (Lily) and "*the whole situation isn't good... the fact that she is allowed to stay up and watch television and then she's obviously tired the next day and... then. That would make her more prone to the seizures*" (Jane, Susanne's Mum). A number also went on to add that if Louise went to bed earlier this would potentially prevent her seizures, or at least reduce their frequency. For example, "*she needs a bedtime routine. Calm her before bed, that'll hopefully stop them*" (Carrie, Lucas's Mum) and "[Louise is] *kinda making herself have seizures... don't like it... if she doesn't go to bed and sleep... then... she should go to bed earlier...*" (Susanne). Knowing the triggers of seizures can help minimise and possibly prevent seizures altogether as children and parents put in place strategies to avoid them.

A handful of parents spoke about their strategies to avoid potential seizures. For example, Monica, Courtney's Mum, reflects: "*we did tend to find that lack of sleep was bringing hers on, yeah. We were always going into her room saying 'right that's enough, telly off cause if you don't get to sleep you've got school in the morning and then you'll be taking a turn'*". Just three children spoke about strategies to avoid seizures; for example, Peter described avoiding flickering or flashing lights: "*I have to look at screens side on or I can't watch... like, if there's anything on the TV with flashing lights I have to go out the room*".

Two further children spoke about less tangible actions they take to prevent their seizures. Maisie spoke about her Mum's ability to stop her seizures happening: "*when my Mum is here to see it. She can stop it. I stay close by*". Maisie feels that her Mum can stop her seizure happening, so she chooses to stay nearby in case a seizure occurs. On a similar level, Emma spoke at great length about her strategies on how to prevent her seizures:

Emma: The first one was I would try my hardest not to fall asleep until eleven which was stupid cause that made me really tired, I mean, I didn't have the medicine then but it still made me really tired.

Int: So did you think that if you were really, really tired when you went to sleep you wouldn't have one?

Emma: I don't know, I don't think so. I think it was just cause it was something that I could do every night and I could hope that that stopped me from having it.

Int: So you could almost kind of control it and stop it from happening?

Emma: Yeah. And then another thing I would do is I would make sure that [Emma's brother] turned his light off first so that I could turn my light off and close my eyes at the same time, and that was like just something I did, so I'd do that and then I'd open them again and it was like just... I don't know why I did that, it was another thing to stop them.

Emma's reflections illustrate her need to control her seizures: there is a sense of desperation and anxiety around having a seizure. These specific rituals offered Emma a form of control over her seizures. Emma appreciates that there is minimal logic behind such behaviours at preventing seizures, yet she continued to use them, the only thing she could control. The past tense of her discussion shows how she no longer follows the rituals, this may be because at the time she had been seizure-free

for over a year. For both Maisie and Emma, their behaviours may not lead to a reduction or the prevention of seizures in reality but remaining close to their Mum or turning lights out in a particular order has given them a sense of control over the unexpected nature of their seizures. All of these tactics are attempts by parents and children to completely prevent seizures from happening. In doing so, the potential for harm is greatly reduced.

Challenges can arise as children and parents seek to avoid the known trigger of seizures creating unexpected consequences. Iain's parents (Derek and Jean) discussed their challenge in relation to Iain's trigger (loud noise, such as a raised voice):

Derek: A man's voice, I've raised my voice to him when he had it, forgetting...
Jean: We just feel guilty don't we?
Derek: ...forgetting that he had the epilepsy and I used to raise my voice, not shout from the rafters but [slightly raised voice] 'Iain!' and before you realised he would have a wee shake and my goodness, I just felt terrible. But then a couple of days later he'd do the same thing again, I'd forget again and...
Jean: It's just something you live with isn't it, but...

The sense of responsibility Iain's parents have to prevent the seizures is seen alongside the guilt they feel of triggering Iain's seizure (or shakes).

Similarly, Esther reflects on the impact her Dad's thinking on triggers has on her:

my Dad's more conscious about my sleep. [...] Because he doesn't want me to have another seizure. [Int: And is that a good thing?] Yeah but it can sometimes get really annoying.

Esther understands and accepts that she perhaps cannot stay up late because of her need to get plenty of sleep but having this restriction can be frustrating still.

Children and parents' attempts to prevent seizures are clearly illustrated. Being able to identify potential triggers and reduce exposure to them can be seen to help children and parents in achieving prevention. Knowing triggers can provide a sense of control over the seemingly unexpected nature of seizures (Moffat et al, 2009). Also, demonstrated were children's own (agentic) attempts to prevent seizures, revealing their own concern at having a seizure. However, knowing triggers can themselves add

a cause for worry, particularly when the trigger is accidentally elicited, tapping in to a felt parental responsibility to keep children safe (Churchill, 2011). Attempts to prevent seizures are often linked and connected to how children and parents attempt to mitigate the uncertainty around seizures occurring and how this can and does influence their lives. This balance of mitigation and risk will now be discussed.

3.2. Mitigating the Impact of Seizures

3.2.1 Assessing the Impact

For 27 parents, their initial feelings after diagnosis and during the early stages of their child's epilepsy, influenced how they felt they cared for their child. Shona, Nicola's Mum, described, "*from the point of diagnosis, we were very much wrapping her up in cotton wool*". Shona clearly wants to protect her daughter. Six further parents also referred to wanting to wrap their child in cotton wool during this initial period. This idea of wanting to protect their child is explained by Christine, Lily's Mum, who added, "*with seizures it's more of a worry factor*". The suggestion that the presence of epilepsy creates more concern for parents, results in them wishing to protect their child from everything. The diagnosis has triggered a greater felt need to protect their children from harm, greater than before the diagnosis was made. Indeed, only three parents reported not changing any behaviours or their perception of risk of potential seizures when their child was diagnosed.

The presence of epilepsy and the need to protect their child from harm causes parents to question things they perhaps would not normally have done previously before the diagnosis. For example, Ellen, Philip's Mum, recalled:

It was little things that at the time he was just trying to learn to ride a bike... and you know it was like he has epilepsy, can he still do that? What if he has a seizure on his bike, can you imagine? He would just stop riding, what if he was in the road...? It would be only a matter of seconds before a car... you know...

Her sudden realisation of potential dangers and what could happen if Philip was to have a seizure is seen. Ellen is questioning what the diagnosis of epilepsy means for even simple '*little things*', suddenly these things have taken on a greater degree of risk with the diagnosis. As she rattles through the potential risks and negative outcomes (that could happen), there is a clear sense of worry and concern.

Furthermore, this questioning of whether Philip can ride his bike suggests Ellen is attempting to negotiate for herself the levels of risk she would be able to accept in the context of potential seizures.

Connected to this, many of these parents reflected on how the epilepsy diagnosis influenced their felt responsibility as a parent. Wayne's Mum, Robyn spoke about this:

it's difficult with a medical kinda thing isn't it, it makes it difficult for people to... they don't want anything to happen to their kids at all and then if it's kinda made a bit more prominent, if their child has got a medical condition as well that you've got that to worry about on top of everything else.

The challenges she feels as a parent of a child with epilepsy are considered an additional compounding factor that influences how much she has to worry and think about keeping Wayne safe. Her parental responsibilities have intensified and are now more of a challenge with the addition of a medical condition.

This deepened sense of responsibility was also connected with an increased sense of vigilance. Across the majority of parent's accounts, there was a repetition of needing to 'keep an eye' on children. Wayne's Mum, Robyn reflected for example, "*we kinda made sure he was watched and things on stairs especially if he was trying to go up and down stairs on his own, in case he did kinda start to go forward [leans forward as if to fall forward]*". The need to watch just in case something happens is seen, illustrating the uncertainty around potential seizures and an attempt to mitigate the impact should a seizure happen. Christine, Lily's Mum, spoke about changes she made after diagnosis to increase her vigilance: "*I had to end up changing the sort of sleeping arrangements a wee bit just so I could keep an eye on her*". After the interview, Christine showed me how she had moved her bed around so she could see straight through her bedroom door into Lily's bedroom (which she shared with an older sister) to check on her through the night. This felt need to 'keep an eye' on their child was seen across the majority of parents' accounts.

In a similar way, Annie, Craig's Mum, spoke about the issue of trusting others in the initial period after diagnosis: "*there was always that panic about what could happen and would they know what to do*". Annie described her lack of trust that other people would be able to manage Craig's seizures if he had one in their presence. This perhaps

indicates her feelings that she is the only one able to provide the care and assistance that Craig would require in event of a seizure. Moreover, Annie's dread of '*what could happen*' reflects and reiterates the feelings of uncertainty around seizures happening and their wealth of potential impact and effect that has been shown in other parent's accounts.

Although increased vigilance was important, only one parent spoke about using an epilepsy alarm to ensure their child's night-time safety. Sue, Rosie's Mum recalled her experiences of using such technology: "*it was reassuring but...but she kept rolling off it so it kinda went off and it was horrendous!*". The epilepsy alarm had provided a degree of reassurance, but the practicalities of using it and frequent false alarms has created a tense atmosphere that disrupted and questioned Sue's vigilance. All of these strategies and overtly protectionist stance parents adopted can be seen as an attempt by parents to prevent seizures and importantly to reduce all potential risk and harm when a seizure does happen.

Children's accounts also focused on the risk of seizures in terms of potential harm. Much of the discussion on potential harm from seizures came through children's reflections on Victoria's comic book story and her situation. Their reflections also appeared to be irrespective of when they were diagnosed, lacking the temporal dimension that parents accounts reflected.

Their reflections on the potential risk of harm around seizures were seen through the repeated use of the phrase "*hurt yourself*" and associated derivatives. This was seen across twenty of the children's accounts. Maisie, for example, spoke the most explicitly about her perceptions of potential harm. When I asked her what could happen if she had a moment (an absence seizure), she reflected:

Maisie: something bad could happen
Int: Yeah? What bad things could happen?
Maisie: Well if you're.... Running... you could fall and hurt your face or something.... Or you could be crossing a road and then just like stop in the middle taking one or ... when you are swimming you could drown or something...

Maisie's descriptions of potential '*bad*' things that could happen illustrate a high awareness of risk and harm potential from a seizure. Even mundane activities such as

running have become tainted by this potential for harm – if a seizure occurs. Other children were less explicit in their descriptions, for example, Philip spoke about his seizures more generally: “*they are dangerous. And sometimes they make you get hurt*”. The sentiment of potential danger and getting hurt is still present. Similarly, the majority of other children focused on Victoria’s story and her potential to hurt herself. Mike described for example: “*[Victoria’s] like worried that she’s going to, like, hurt herself while having a seizure*”. These different levels of description all centralise around the notion of risk and potential harm that could happen if a seizure occurred. Through these reflections, their worry about the potential impact of a seizure is seen.

As much of this discussion in children’s accounts was through the lens of Victoria’s story it is challenging to say with certainty as to whether these thoughts are an accurate reflection of how they feel and perceive their own safety around when seizures happen personally. As most of the sample had well-controlled epilepsy with minimal seizure activity, it could be suggested that the direct and immediate risk and potential harm has reduced. Whilst their seizure frequency has dropped, it has influenced how they feel about these aspects of managing seizures. This is illustrated by Maisie and Philip’s quotes above. They reflect the personal dangers and potential harms, and both were (at the time of the interview) having regular seizures.

In six children’s accounts, there was a greater focus on the restrictions they felt on their lives because of their epilepsy diagnosis and the attempts made to mitigate the potential harm and impact of prospective seizures. David explained, for example:

- David: Like, I have them [seizures] and I’m not allowed to do very much.*
- Int: Oh that’s not good, so what kinda stuff are you not allowed to do?*
- David: I wasn’t really allowed to go outside very much. Couldn’t go to the park without someone with me.*
- Int: Who was allowed to go with you?*
- David: Usually one of my bigger sisters or my Mum and Dad.*

David’s freedom to go out to the park is greatly reduced in his perspective due to his seizures. Even when he is allowed, it is only if a family member accompanies him adding a restrictive complexity to the activity. Similarly, Esther reflected: “*Well kinda stops me doing things, I’d rather not have epilepsy, it’s just annoying. [...] Well, like, you’re not allowed to do open water activities for some reason*”. The repetition of

epilepsy '*stopping*' her from and '*not allowing*' her to engage in certain activities is evident. This replicates David's phrases and those found in other children's accounts.

These reflections on being '*not allowed*' and '*stopping*' doing things could be seen as a reaction to the parents wishing to protect their children in their attempts to manage and mitigate the impact of seizures. Although none of the children directly assigned any responsibility or blamed anyone for not being able to do things. Some children did allude to their parents or the school being the ones to stop them participating or doing certain things. Furthermore, through using these particular words, there seems to be no grey area seen by these children. Instead, a hard line of '*not allowed*' is being heard and felt by children. This could allude to the limited negotiation that has taken place around these restrictions from children. Moreover, this could perhaps reveal how the '*stopping*' of these activities has been explained, or not explained to children. This point regarding explanation was further made by ten children who did not understand why Victoria's Mum (from the comic book vignette) would not allow Victoria out to play with her friends. As Yasmin reflected: "*I don't get it, why can't she play outside with them?*".

Children's reactions to mitigating the potential impact of seizures through reducing or restricting activities also had the effect of making them feel different. This suggestion of being different was seen in sixteen children's accounts. Maisie, for example, reflected on where she can play: "*Sometimes only in the back garden and sometimes I don't get to at all.... Not like them [points to friends on magnetic board]... Not very, very, very different, just a little bit.*" Maisie's awareness of the areas she can play in being different and more reduced than those of her friends reflects in her feeling a '*little bit*' different. David also reflected more broadly that his epilepsy made him "*kinda feel a bit different*". Incidentally, twelve children suggested that Victoria would be feeling different from her friends because of her restrictions around where she could play.

In contrast to this, seven children did not feel different or restricted, nor felt that their life was not affected by their epilepsy. For instance, Peter reflected on his epilepsy: "*it doesn't affect me that much cause I can go out with my friends*". There is, according to Peter, minimal felt impact of his epilepsy (or his potential to have seizures), there are no restrictions on him going out and seeing his friends. A similar sentiment was

provided by Alex, who whilst we were discussing what he liked to do outside and the impact of his epilepsy on this, reflected: "*I'm, well...it isn't different...*". These seven accounts could feasibly be illustrative of an absence of felt restrictions imposed by others. This lack of felt restriction results in them not feeling different or the feeling that their epilepsy is influencing how they live their lives. Though it does contradict findings from chapter 4 that indicated a sense of difference was felt about having epilepsy.

Parents also discussed these feelings of their child being different, Charlotte, Phoebe's Mum reflected, "*having epilepsy does change their childhood*". The implication being that the presence of the condition changes how a child experiences their childhood and perhaps how they are treated more broadly. This was seen through parent's attempts to protect their children and reiterates the notion that illness has the potential to threaten 'normal childhood'. In attempting to explain to David just after he was diagnosed why he was unable to climb trees anymore, his Mum, Colleen, recalls a conversation they had: "*he said 'I can't do anything, my life's ruined cause I've got seizures', 'well no, it's just a kinda safety thing with some stuff'*". Colleen is trying to explain the balance of risk around potential harm from seizures and his previous sense of freedom and adventure.

3.2.2 Balancing and Navigating the Impacts

This tension between mitigating potential impact of seizures and allowing children to do everything that their friends and peers are doing was heavily reflected in parents' accounts. All of the 27 parents who spoke about their initial concerns and wishes to completely protect their child recognised that a balance was needed. Shona, Nicola's Mum, explains:

if I had my way I'd keep her in the house and not let her go out, you know, because it's in the back of your mind 'oh what if she has a moment' but, you know, I can't... I can't stop an eight-year-old from going out and playing with her friends.

Shona explains that as much as she would feel more comfortable keeping Nicola at home, it was perhaps not in the best interest of her. The reference to '*an eight-year-old*' also suggests that Shona is attempting to provide her daughter with a 'normal'

eight-year-old life and connected experiences irrespective of her diagnosis and potential to have seizures.

There was also the sense of a personal need to find a balance, as Craig's Mum, Annie explained: *"I don't think, don't think you could maintain that panic and that intensity and things. If you did that you would drive yourself crazy and stuff [laughs]"*. The suggestion that as a parent it would be too challenging to maintain the level of vigilance and alertness to potential risk is seen. The duty of responsibility can be too intensive in this context of childhood epilepsy. Finding the balance of appropriate mitigation from harm and risk is however challenging for parents. Geoff, Keira's Dad, reflects: *"one of the most difficult things about having a child with epilepsy is deciding what risk to accept"*. The sense of overriding responsibility parents hold for their child is seen alongside the challenge of attempting to keep them safe by protecting them from the risk of harm creating an inherent contradiction and tension.

A handful of children also recognised this tension arising from balancing the potential risks of harm from a potential seizure and forms of independence in reflecting on Victoria's story. As Iain reflected on the story, he stated, *"I'm not too sure about that. Hum... it's a bit complicated"*. Phoebe similarly reflected: *"well I feel for Victoria but I don't know. Hum she has epilepsy like me, but... er... Because that has something to do with it"*. Phoebe and Iain reflect the complicated nature of such a decision.

Connected to this, half of the children discussed, through Victoria's story, compromises that could be made to restrictions that had been placed on Victoria to mitigate the impact of her seizures. Three children suggested the use of technology, as Yasmin suggests, *"a phone, she could call her Mum and, like, her Mum could call her, like, where are you or, like, what happened, yeah, she could talk with her Mum"*. The involvement of Victoria's friends was also suggested by six children. For example, Philip felt that, *"She [Victoria] should have been allow to go out and play because she. Because if she is going to play with her friends, they can obviously look after her in case she gets hurt"*. These suggestions of compromise illustrate how children are engaged and understanding of the potential risks around seizures. Whilst also demonstrating children's potential agentic involvement in negotiating and mitigating the risk and the decisions involved.

The shift in beginning to renegotiate and rebalance their risk acceptance was heavily connected to the frequency and the reduction of seizures for parents. Katherine, Peter's Mum, explored this:

initially I just wanted to wrap him in cotton wool and keep him at home and, you know, watching him constantly, but I think the longer that it went without him having a seizure the more confident I got and the less anxious I got about letting him go out and play with his friends and that sort of thing

Katherine's feelings of 'wrapping him up in cotton wool', are seen to be reducing as he went longer seizure-free, allowing her confidence to build and the acceptance of risk to seem easier. This sentiment is similarly reflected by Don, Mike's Dad: "*At the start we were just a wee bit... just sort of keep an eye on him more, but now, now he's just like normal. He doesn't have them now*". Don's reference to Mike being 'normal' now that his seizures have been controlled illustrates how these parents begin to feel comfortable, attempting to provide their children with ordinary childhood experiences. The controlled nature of their seizures facilitates finding the balance.

Connected and irrespectively linked to seizure control is medication success. The success of medication in controlling seizures was also seen to assist this shift and assisting in the balance. Wendy, Mike's Mum, explores the comfort medication brings when an attempt was made to wean Mike off medication previously goes wrong:

when he is weaning himself off it I don't like it, I must admit, I get worried [...] I was actually on the verge of saying 'just put him back on his medicine' cause he was... we were watching him all the time and you couldn't really let him go out and play with his friends because if he was out and took one

The comfort of having medication offers Wendy a sense of additional protection for Mike. With the medication, she is much more relaxed about giving him opportunity to go out with friends, reflecting a lower concern of the potential risks. As the quote shows however, once this security provided by the medicine has gone, Wendy becomes more vigilant, watching him all the time, and trying to keep him safe, the additional protection is gone. The relief the medication provides is clear. She would rather he went back on the medication, as this provided 'protection' to make it ok for her to allow him to go out and have fun. A similar sentiment was voiced by Verity, Esther's Mum, who stated, "*I don't want her coming off them if they're working at the moment*" in reference to Esther's medicine.

Coupled with a low frequency or controlled seizures and medication being seen to have the desired effect the support received from healthcare professionals, primarily Epilepsy Specialist Nurses (ESNs), was referred to by the majority of parents as helping them achieve a balance. For example, Carrie, Lucas's Mum, recalled:

I mean one thing [ESN] did say was you know keep everything the same. You don't have sorta, how did she put it, you basically didn't have to stop him doing this or that just because he has got it.

Likewise, Katherine, Peter's Mum, stated: *"[ESN] spoke to us quite a bit about it and said 'you can't lock him away [laugh] and you need to try and keep things as normal – for want of a better word – as possible'".* There is the suggestion from these accounts that the ESNs have been fundamental in shaping and influencing the level of risk parents seem to be willing to accept. This input could serve as a form of legitimisation for parents to allow them to reduce their attempts to mitigate potential harm and accept the risks of harm in balance with what could be described as typical childhood freedoms.

In reflecting on these factors, many parents spoke of how it caused them to shift how they manage seizures and their unpredictability and risks of harm. For example, Sue, Rosie's Mum, recalled a particular decision: *"she was dying to get bunk beds and we were a bit tetchy about her having bunk beds but we kinda relented about it a year ago when she stopped having seizures and the medication controlled her seizures. So why not".* This relenting has coincided with the change in Rosie's condition, reducing the concern. This was reflected by a number of other parents too: *"now we don't even... we don't stop him doing anything, like going out on his bike or swimming or anything"* (Don, Mike's Dad); *"I've probably relaxed off quite a bit"* (Colleen, David's Mum). Parents appear to be more content with the presence of epilepsy and the uncertainty associated with seizures. This can be seen through their felt ability to achieve a balance and feeling that a more 'normal' level of risk has been found.

Despite this sentiment of a balance being struck seen across the majority of parents' accounts, it was still challenging for some parents to find a comfortable balance for all. Geoff, Keira's Dad, spoke about his discomfort with some decisions he has made in this attempt to create a balance:

we had this discussion between the two of us [Mum and himself], so [Keira] wants to come home from school alone and we've been letting her, there's no main roads, it's just along the road the school that she goes to, but I do feel concerned about that, I'm not comfortable but at the moment she's coming home from school on her own and I'm not comfortable with that. At all.

Although he has agreed to allow Keira to walk home from school there is an obvious discomfort with this decision around the level of risk of harm involved. Geoff is seen to justify his decision through logic, suggesting that there are no main roads etc. but still the emotional concern remained and is illustrated through his obvious discomfort.

However, five parents did not discuss or suggest any form of balance or shifting of the levels of risk they would accept in their attempts to mitigate the impact of seizures as has been illustrated in the section so far. Ash, Yasmin's Dad described how vigilant he and his wife are with Yasmin:

We always one with her, even we don't leave alone with sister [...] Because of epilepsy, because we must always alert. Always alert because in a minute she can have that seizure, so we don't... even I doing the garden, I keep door open and ask her to sit here, not even upstairs, I ask her to sit here otherwise anything happen just call me, yeah it's always better.

Ash reveals an intensive state of constant alertness in case Yasmin has a seizure, choosing to keep her very close to either him or her Mum. The unpredictability of her seizures and because her epilepsy has created a sense of needing to be 'always alert', has resulted in this high level of vigilance and protection of Yasmin. Yasmin had no (clinically or self) reported seizures for the previous year and a half when her Dad was first interviewed, suggesting that even though the frequency of seizures has curtailed, Ash's inclination to protect and conception of risk, has not.

Similar to Ash (Yasmin's Dad), Sharon (Maisie's Mum) felt Maisie "cannot go to her friend's house and stuff, or even to the shop at the bottom of the road", before adding later: "at the moment I just didn't let her do it so it is more like if she takes her medicine and is seizure free then you know all of this, this I would be ok to happen". Sharon connects the acceptance of risk with medication being taken and seizures becoming controlled. However, when I interviewed Sharon for the second time (five months after the first interview), I asked about this and whether Maisie was allowed

to do 'more things' now. At the time, her last seizure was six months ago. Sharon responded: *"of course not"*. No further details were given, despite probing. Consequently, the reduction in seizure frequency or the appearance of seizure control does not always equate to parents reassessing their reactions to mitigating the impact of seizures and their levels of risk acceptance.

These thoughts and approaches to risk and their attempts to mitigate all potential harm led the parents to stop particular activities that they considered too unsafe for their children. Jane, Susanne's Mum, for instance, spoke about swimming lessons: *"the swimming, I mean she was having lessons so we stopped her. We had to stop her lessons...erm... cause of it"*. Likewise, Sharon (Maisie's Mum) reflected on why she had to stop gymnastics: *"she had to give up a lot of her activities like gymnastic as she couldn't go the beam as she'd be having them all the time"*. These activities have been stopped as a direct result of their children's diagnosis. For these parents, the risk of harm has been deemed too much.

Children's reflections on these restrictions were minimal and mixed, for example, most of these children did not mention any restrictions or the stopping of particular activities. Yasmin however did suggest that she would like more freedom and independence as we spoke about the school she attends:

Yasmin: Yeah, it's close by. You just need to, like, walk about five minutes.
Int: Yeah, oh that's good isn't it?
Yasmin: So near.
Int: So do you walk to school?
Yasmin: I've never walked myself.
Int: No?
Yasmin: Just Mum or Dad.
Int: Do you wish you could walk by yourself?
Yasmin: Yeah. I want to. Or with friends. But no.

Yasmin's reflections indicate a wish to walk to school by herself or with friends. Her Dad's attempts to mitigate the potential impact should a seizure occur are seemingly blocking this wish though. Perhaps illustrating Yasmin's feelings of being unable to negotiate or provide some compromise around her Dad's attempts to mitigate harm and risk. This idea of negotiation and compromise will be explored in more depth in the following section on roles and involvement in treating and managing epilepsy.

It is not always solely parents and children that must navigate the balance of risk and managing the potential of seizures happening. Rather, teachers and other care providers are also involved in maintaining this balance. Three parents reflected on this balancing by others who are actively involved in caring for their child. For example, Christine, Lily's Mum, described a situation with one teacher in particular:

Christine: one teacher actually sat her down in the middle of the classroom because they were worried in case she was going to have a fit and they just sat her on this cushion, so I was a wee bit miffed at that.

Int: Were the rest of the children just sat on chairs?

Christine: Yeah, aye everybody else was on a chair.

The actions of the teacher are unusual causing Christine to be annoyed. The teacher's actions served to segregate Lily from the rest of her class, revealing and highlighting a difference between her and her peers. This connects to the discussions of disclosing epilepsy covered in the previous chapter (4) as well as reinforcing children's feelings about being perceived as different. Moreover, it also reveals a lack of understanding of epilepsy and the potential risks and harms of seizures from the teacher.

In a similar interaction with a school, Cathy, Melanie's Mum, describes a different situation:

the thing that's bothering her [Melanie] just now is she's just done a block of swimming lessons with the school, although she can swim like I say, but they won't allow her to go in the deep end and she couldn't understand why, but I don't think they'd actually explained to her cause I obviously have to fill in the form that she has a form of epilepsy and, of course, the school won't take that risk.

For Cathy, the school has elected not to take the risk of allowing Melanie to swim in the deep end of the swimming pool because of her epilepsy. Cathy seems accepting of this, perhaps appreciating the dissimilarity in risk perspective that others could adopt. However, she demonstrates the considerable need to be clear about these differences in perspective around risk and mitigation. Melanie has been left wondering why she is unable to do the things her peer group are presumably doing. There is instead a need to create a shared understanding about risk and different perspectives and levels of acceptance. Both Melanie's and Lily's situations reflect a difference in risk acceptance that can be seen as going against what parents had

accepted themselves. This difference can also serve as an indicator of difference between children with epilepsy and their peers as well as having implications for disclosures of epilepsy.

These sentiments were apparent whilst four children spoke about school trips. For example, Susanne explained: "*we went this school trip and I couldn't do... go out on the boat because of it. Everyone else went canoeing but I didn't get to go*". When I asked how this made her feel, she added, "*sad. Really sad. I would have liked to have gone canoeing...*" She is sad to have missed the opportunity to go canoeing, just like the rest of her peer group. This separation of not being able to do the same things as their peer group and missing activities was also evident in a handful of children's reflections. Additionally, neither Yasmin nor Courtney have ever been on a school trip due to their epilepsy.

As shown, most children reflected that attempts to mitigate the impact of potential seizures by restricting activities made them feel different (Harden et al, 2016). Parental responsibilities were described as being intensified with the presence of epilepsy and possibility of seizures, replicating previous studies exploring other childhood chronic conditions and disabilities (McLaughlin and Clavering, 2012). Successful medication was seen as a means to accept risk, providing a sense of protection for many parents (Niedel et al, 2013; Webster, 2017). The level of risk parents conveyed also appeared to constrain children's agentic opportunities (Wyness, 2015). Children additionally indicated their minimal influence on how their activities were restricted serving to further constrain their potential agency.

3.3. Summary

Many children and parents attempt to mitigate and manage the uncertainty of seizures occurring by balancing risks and adapting to the changing condition in different ways. These attempts are accepted by many children yet can cause conflict due to children's lack of autonomy in the decisions and restrictions (Christensen, 1998). Parents reactions to the uncertainty of seizures were variable and could be linked to the perceived severity of the condition, whether the medication was deemed to be working and through the encouragement of others to '*let go*', although there was not always a desire for risk. These thoughts intersect with discourses of risk and

parental responsibilities, as well as having connections with children's and parents' wishes around disclosing epilepsy and the felt stigma around this (Niedel et al, 2013; Benson et al, 2017).

4. Summary

In summary, this chapter has explored children and parents' experiences of their treatment and the management of their epilepsy. Children's knowledge of their treatment regimes and management of seizure risk is varied and interdependent. It is structured around their own experiences, drawing on their experiential expertise (Ironside et al, 2003; LeFrancois, 2007), as well as what parents have told them. The knowledge and understanding created is thus different to the clinical knowledge of healthcare professionals or the insights parents develop due to being heavily mediated by others (Brady, 2014). This links to the findings of the previous chapter (4). Treatment regimes have shown to be multidimensional and embedded in to the routine of everyday family life. At times, the dynamic nature has been shown as parents and children accommodate medication changes.

Parent's revealed a sense of responsibility and risk appetite around the mitigating harm from potential seizures through their management of children's activities and quests to protect them. These insights reveal the further complexities of living with and managing childhood epilepsy for parents and the sense of responsibility parents having in ensuring the treatment works (Bluebond-Langer and Korbin, 2007). Parent's attempts (and felt responsibility) to protect their children, reiterated the notion that illness has the potential to threaten a childhood that tends to be considered normal (Tisdall and Hill, 1997). Many parents spoke of the changing condition shaping how they managed this, with seizure frequency and medication success negotiating their balance of risk for their child. All of which constrained and thinned children's agentic opportunities (Klocker, 2007). Despite this, many children reflected on the strategies they had crafted to ensure their medication was taken (palatably), clearly demonstrating children as agentic actors. These strategies were often overlooked, perhaps unrecognised, by parents. Thus, reflecting how children's enactment of agency does not always require an invitation from parents or others (Moran-Ellis, 2013).

Chapter Six: Roles and Responsibilities in Treating and Managing Epilepsy

1. Introduction

The previous chapter (5) examined different components of treating and managing epilepsy, illustrating children and parents' understandings and experiences of medication, and seizure prevention, management, and mitigation. It revealed how childhood epilepsy is conceptualised and embedded in their lives and the agentic contributions children make in their treatment and management of their epilepsy. Building on this, understanding what roles children and parents have and take on within these practices and activities allows for a deeper exploration of care and children's involvement in the context of their epilepsy.

This chapter will explore how roles of treatment and management are created and perceived by children and parents. Further exploring the nuances to these roles and responsibilities each family members adopts in this caring context. The ways in which children's involvement is facilitated, negotiated, and constrained will be explored. How and the extent to which children are involved in aspects of their care can illustrate opportunities and invitations to be agentic, engaging children in their condition and its care. Much of the discussion around these themes centred on the interview tool 'magnetic families and friends' – an interactive board that allowed children to visually demonstrate different aspects and levels of involvement in the treatment and management of their epilepsy.

The chapter will firstly highlight the importance of parents' in the roles of treatment and management. Children and parents' accounts on their and others involvement in medication and managing epilepsy will then be explored. Finally, a summary will draw threads from this and the previous chapter (5) together to better understand children's agentic capacity and how this is (or is not) used in regard to their treatment and management.

2. Importance of Parents

From children's perspective, parents hold significant roles, and responsibilities, in the treatment and management of their epilepsy. For 12 children, there was no, or only minimal, distinction made between 'parents', for example Rosie described, "*my mummy and daddy are acting level with this stuff*" in relation to what each parent did in terms of treatment and management of her epilepsy. Similarly, when I asked Iain whether there was a difference between what his parents did, he responded: "*They do the same thing really, no different*". In many of these accounts, parents were seen as interchangeable.

Six children felt their Mum was more significant in their treatment and management of their epilepsy, with their Dad providing assistance when available. As Craig discussed his family's roles he spoke about the differences between where he placed his Mum and Dad on the magnetic board of care: "*Well it depends what time. If it was like... when my Dad wasn't home. He used to be home about half 8. So it would normally be my brother and my Mum*". The reality of working parents often creates this distinction and differences in perceived involvement in looking after children. Conversely, two further children felt their Dad was more involved; their Mum again was seen to be present and providing support when available. There was no reflection on why from either child, for example, when I asked Yasmin she simply stated, "*my Dad, he'll do stuff more*". Two families involved in the study were single parent households and one child did not differentiate between his parent or his older brother suggesting instead that his whole family was involved in treating and managing his epilepsy. Parents themselves did not differentiate between their roles, and rarely spoke about any gendered differences in their roles through their accounts.

3. Involvement in Medication

When discussing treatments and specifically medication and roles associated with it through the magnetic families and friends' activity, eighteen children placed themselves on the '*most*' involved side of the board. Their thoughts on their chosen placements on the board focused primarily on the act of taking medication: "*I just do it [mimes popping a tablet into her mouth]*" (Yasmin), and "*like this [mimes a spoon going in his mouth]*" (Mike). Physically taking the medication was seen as their role and an illustration of how involved they feel in their treatment. Such thinking about

this role is perhaps natural for children: they are inevitably the one that must take their medicine, not anyone else. This role was for most children their only self-reflected role in terms of their treatment.

Ten children also stated that they were responsible for remembering and reminding their parents about their medication. This was seen as a shared role with their parents. As Craig described, "*Sometimes she forgets and I remind her*", and similarly, Peter stated "*I usually remind my Mum or Dad*". This shared responsibility was seen as an important role to these children, illustrating an important aspect of their perceived involvement, their agentic contributions, and their understanding of the importance of their treatment. Incidentally, these children also had a better understanding of the names and dosage of their medication, as was discussed in the previous chapter (5).

Children's siblings were also identified as sharing this responsibility of remembering medication by three children. For example, Susanne explained her younger brother's role: "*Like at tea time and breakfast he always says 'take your tablets [Susanne]' just like... not as a joke but... he says it funnily. 'Take your tablets [Susanne]' [said in a funny adult, authoritative, sounding voice]*". Similarly, Alex explains: "*Dad gets it out for me and then I take it. And then sometimes my brother helps, he gets my tablet out as well*". Alex's and Susanne's brothers are assimilated into the treatment practices, exemplifying a shared sense of responsibility and understanding of its importance for the whole family.

Children's role in taking medication was further extended by three children who also spoke about their involvement in administering their own medicines as well as being responsible for taking them. For example, Courtney explains "*I just take it out the [pill]box and then just take it*". Even though her medication is already placed in her pillbox by her Mum at the start of each week, Courtney still felt that she took her medicine by herself. Indicating a sense of her own agentic competency and self-responsibility. In discussing taking medicines by themselves with other children there was a mixed response. Two children actively felt that it would be a bad idea, as Esther explained:

Esther: *Well it's a bit dangerous just me being able to help myself.*
Int: *Why's it a bit dangerous?*

Esther: Because if I, for example, take the wrong day and I don't realise I've taken the wrong day then I've got a bit of an issue.

Esther, felt that it would be unsafe to manage her medicine herself. The use of the word '*dangerous*' indicates the Esther is aware of consequences if she takes too many or not enough of her tablets. This perhaps suggests that she did not feel competent enough to manage this important aspect of treatment by herself in light of these potential consequences: the risk was deemed too high.

Most children seemed to be content with having their medication passed to them, keeping their own engagement and involvement in the process low. When I asked Abby if she would like to make her '*cocktail*' of medications she responded, "*well, not really no [...] because I just want to rest for a bit [laughs]*". It appears that Abby has no inclination to be involved in taking her medication. This sentiment is mirrored in, Abby's Mum, Shirley's account when she spoke about Abby's involvement in medication, "*she has never been particularly bothered... she is quite happy to have it handed to her*". This indifference to further involvement in the medication taking process, beyond the act of physically taking medication, was seen across half of children's accounts.

Potentially, hampering their involvement in the process, three children reflected logistical challenges with administering and taking their medication. For example, Melanie felt it was impossible to attempt to take her medicine alone due to the bottle: "*It's a children proof one*". This safety precaution restricts Melanie's attempt to administer her medication herself, even if she felt capable and willing to do so. Two parents also reflected similar issues, for example, Christine, Lily's Mum, reflected on the medication bottle that Lily had prescribed:

you can't actually get that to stay in unless you're like a Mr Muscle Man, then you can't get the lid on top of it, so they should devise an easier way [laugh] for children to actually do it themselves

Christine went on to add:

I remember that time [Lily] done it and she ended up spilling about half the bottle!

The impact of having a medication bottle that was hard to open and challenging to get the syringe in to measure out the medicine is clear. Christine has obviously allowed Lily to try administering her own medication, without much success in attempting to facilitate Lily's involvement in her treatment. These logistical challenges could perhaps restrict children's opportunities to be actively involved in taking their own medicine, if and when they choose to.

Parents discussed their child's involvement in the administering and taking of medication in detail. Children's involvement and the extents to which this was encouraged and facilitated, according to parent's perspectives, was variable. Judy, Jack's Mum, spoke about Jack's level of involvement in taking his own medication, recalling that:

[Jack] took his own and I mean he just, it was just a straight forward to spoonfuls out the bottle, he was quite happy to you know manage it himself [...] he was coming through and doing it himself, I mean usually I would be here making dinner anyway you know. So he just came through and took his two spoonfuls and then went away

Jack, according to his Mum, was actively engaged and involved in taking his medication, illustrating to her his sense of responsibility, understanding, and competency over his treatment regimes. Judy has naturally allowed this to happen, facilitating Jack as he took on this responsibility.

Colleen, David's Mum, however felt: *"If you didn't remind [David] he wouldn't remember to take it, he wouldn't remember to take it"*. Suggesting that David has little involvement or interest in administering his medicine or remembering it and indicating no engagement in the process. Yet when David himself spoke about remembering and getting his medicines, he stated that, *"Well sometimes it's my Mum, sometimes it's my Dad and sometimes I just do it."* The variations in David and his Mum's accounts illustrate the difference in perceptions of involvement from children and parents. This in itself can create frictions as children's quest for autonomy could go unrecognised or facilitated.

Some parents detailed various attempts to encourage their child to become more involved in the process of taking and administering medication. For example, Ryan, Emma's Dad, detailed, *"She's got an alarm on her iPad which sometimes, supposedly*

reminds her". Emma's parents had attempted to use Emma's own iPad alarm system to encourage Emma to take on some responsibility of remembering to take her own medicine. Similarly, Verity, Esther's Mum, recalls:

if we actually get her to remember it would be quite handy but I'm torn in that respect because on the one hand I want her to get into the habit herself and for it to be very much part of her life, and [Eric, Esther's Dad] was trying to tag it to cleaning her teeth right, 'if you're cleaning your teeth [Esther] then that's the trigger have you taken your medicine?' but, you know, getting her to clean her teeth would be a start wouldn't it!

Verity is eager for Esther to establish the routine of taking the medication by herself, encouraging her to take on the responsibility. Connecting the taking of her medicine with brushing her teeth is Esther's parents' attempts to ingrain this process of taking medicine into her routine and day-to-day responsibilities of self-care that should be developed as a child gets older. As noted by Verity this has not proved successful, but notably neither has getting Esther to brush her teeth. There appears to be a limited quest for the increased autonomy and additional responsibility from Esther.

The attempts at encouraging involvement were not always successful. As Ryan, Emma's Dad, reflected: "*Yeah we try and get her to take some ownership but she's reluctant!*" When I asked Emma's parents why they thought she was reluctant, her Dad, Ryan, responded: "*She's still a child*". Ryan went on to explain further "*you have to remember that, well what was she, eight or something when it all started, so you can't really expect an eight year old to take ownership of that sort of thing.*" The suggestion is that Emma's lack of engagement or involvement in her treatment is due to her young age, and perhaps that she is *too* young for this responsibility. Illustrating perhaps that parental protection can inhibit children's agentic development.

Interestingly, Julianne, Emma's Mum, went on to add that, "*it doesn't feel like an issue because we're sort of looking at probably coming off the medication from September so it's not like we have to worry that she won't, you know, in future it'll be an issue, you know, we're going to be finished with it soon I think*". This illustrates that perhaps Emma's parents feel that encouraging a sense of responsibility and related competency skills in administering and taking her medication do not necessarily need to be developed.

Involving children in any aspect of their treatment at home was however not always seen as a positive by parents. A handful of parents actively discouraged any form of involvement from their child, for example, when I asked Iain's parents (Jean and Derek) about Iain's potential involvement, they explained:

Jean: I don't think I'd trust him...
Derek: He's too young.
Jean: ...I wouldn't trust him

Derek went on to add:

we control his medicine at the moment and give him it [...] as far as I'm concerned, as long as he's taking medication, his Mum or I will always make sure that his medication is made up and that he's taken it.

Iain was deemed too young, again raising concerns allowing responsibility by linking his potential competence with his age. These parents viewed managing medicines as their role and importantly, their responsibility. Sharing this role with their child was felt to be unsuitable.

In terms of treatment, levels of involvement varied across children's accounts, as did their individual quests for more or less involvement. These quests can however be contradictory to what parents would prefer. Where children are able to assert their preferences, it is seen to benefit how they experience their treatment and the management of their epilepsy. Dissatisfaction with their involvement is seen to discourage children from being involved and illustrates a passivity towards their care (Christensen, 1998). Children reflected medication preparation, administering and reminding as key roles for parents, highlighting their views of parental responsibility.

4. Involvement in Managing Epilepsy

As explored in this chapter (5), management of epilepsy is primarily seen through how children and parents manage seizures, the uncertainty and their attempts to mitigate their impact when they do happen. From children's perspective, similar to their discussions of treatment, parents hold a significant role in the management of their epilepsy. Providing reassurance, administering first aid and getting help were seen as

key roles parents had in children's view of managing their seizures. For parents '*being there*' when seizures happened, was key.

Nineteen children discussed this notion of parents being present during and after a seizure, for example: "*they are always there*" (Abby), "*Mum and Dad are both over here [most involved in seizure care] because they are there for them [seizures]*" (Peter), and "*Dad will say it's okay. Also my Mum, my Mum and Dad just say like the same, so 'you're okay, you're okay. They're always there*" (Yasmin). The frequent referring to the sense of '*being there*' provides great reassurance and comfort for these children. Two children went slightly further with these, suggesting that their parents '*protected*' them. For example, as Maisie discussed what happened when she had a seizure, she explained that her Mum would: "*keep an eye on me ... You know....protect me*". The idea of parents being protectors resonates the concept of '*being there*' and reinforces children's view of parents' role in keeping them safe and providing extensive reassurance through their presence.

Siblings and friends were also seen to be greatly involved in managing seizures from children's perspectives. For the majority of children, siblings' and friends' roles were described as getting help, keeping them safe and for '*being there*' for them when they had a seizure. This was particularly acute when children were at school. For example, Craig reflects:

say I had a seizure [brother] would do it but then [friend] would be beside, [brother], and then [friend] would say what's happening and [brother] would say, he's having a seizure then, I... see if [brother] needed to put me in the position. [Friend] would go and tell the teacher.

Craig's brother is heavily involved in managing his seizures if they would happen at school (and at home). His brother is aware of what to do and will ensure he remains safe by putting him in the recovery position if needed; his friend is also part of the process by getting help. Similarly, Iain reflected on his brother's role at school if he had a shake: "*He'd come and probably ask if I'm alright and then... ask if I'm alright and then... and then... make sure I'm alright and I'm okay*". This reiterates the '*being there*' reassurance that was so strongly seen when discussing parent's roles, illustrating how vital siblings and friends can be in event of seizures. Not all children, however, reflected friend's involvement in managing seizures; where there was no

mention, it was often linked to children not wishing to disclose their condition to their friends (as discussed in chapter 4). Furthermore, there was no mention from parents about other children's (siblings nor friends) roles in assisting or managing their child's seizures.

Regarding parents' accounts, there were very few discussions of their own role in seizure management beyond their descriptions of attempting to mitigate the consequences of their child's potential seizures as explored in chapter 4. This in itself reflects how important preventing any harm was for parents. A few parents however did speak about just how challenging they found seizures to deal with. Craig's Mum, Annie reflected after discussing Craig's seizures, "*I think that's it... it's probably been hardest part of his care*". Colleen, David's Mum, further explained the challenge: "*The actual physical caring for him I'm fine with that, completely fine, but it's a shock when you see your own child having a seizure*". Seeing their child have a seizure can be challenging, the emotional shock it causes can test parents and their resolve to look after their child. This perhaps demonstrates a hidden dimension to managing seizures that parents must contend with aside from visible and articulated roles.

In terms of involving children in managing seizures, a handful of parents recalled actively involving them in managing and mitigating the impact of potential seizures. This was primarily achieved by ensuring that their child understood what to do if a seizure happened. Shona, Nicola's Mum, for example, recounts the conversation she had with Nicola around this:

we've sat her down and we've said to her 'right okay, what would you do if you were at the park and you had a moment?' so the park's just along the road, it's not far, 'what would you do if you had a moment?' so she said 'I would run home' and I said to her 'no, don't run home because...' though there's not a road that she has to cross over but, you know, I said to her 'well if you were at the other side of the road, no you don't run because you would run across the road, so you would just sit down, wait for it to pass and then you would come home'. So yeah she knows, she's clever, she's not silly, she knows that if that was to happen then, you know, there's a plan that that's what she does.

This recalled conversation illustrates Shona's attempt to ensure that Nicola has a plan: an understanding and an appreciation of the potential risks if something should happen whilst she is at the park. Also, the explicit mentioning of Nicola being '*clever*,

not silly' illustrates how Shona trusts that she will do the 'right' thing and keep herself safe should something happen. This in itself reflects a trust in Nicola's competency around seizure safety.

In a similar vein, a handful of children reflected on their own involvement in seizure management through their roles in attempting to mitigate the consequences of seizures. Peter, for example, spoke about his plan for if he had a seizure outside and away from his parents, stating that: "*I have an emergency number on my phone and my Mum and my Dad they dial it and they call my Mum or Dad and they call an ambulance too*". The '*they*' he refers to are his friends; they have been instructed to use the emergency phone if he has a seizure. Peter seems to be accepting of this and is understanding of his need to have the phone with him. Katherine, Peter's Mum, reflects on how she feels he deals with this necessity: "*He seems okay with it, I'm sure he feels that I worry too much, he calls me the fun police! Yeah but he knows why, he seems to know why we're just making sure that he's safe really*". Despite Peter perhaps feeling that his Mum is occasionally over the top, the appreciation of its importance is clear through both their reflections, indicating a shared understanding and felt competency in Peter's (and his friends) ability to keep himself safe. The discussing with children around what to do if seizures happen illustrates how children themselves can be integrally involved in their managing of seizures and provide parents with a sense of reassurance on seizure safety.

For the majority of parents and children there was very little further discussion on children's roles or involvements in the management of their seizures. This could be due to children often not being aware of seizures either happening or have warning of when they are about to happen. As already discussed in chapter 4, only four children experienced auras warning them of an impending seizure. These children demonstrated how they used these warnings to get help (Emma) or to ensure they remained safe (David), indicating a level of involvement and importantly engagement in their own safety. Additionally, six parents did reflect on how their child would tell them after a seizure happened, as Ash, Yasmin's Dad stated, "*she always tells when it happens*". Iain also reflected this as well, telling his teacher: "*Normally she doesn't see it, sometimes she does but normally she doesn't, but then I go and tell her and then she'd say 'are you alright?'*". Being able to tell parents about their seizures was seen as an important aspect of children's involvement in their seizure management for

parents and children, particularly when the seizure (usually absences) can go unnoticed.

However, this insight and involvement cannot always be achieved; three parents detailed how their child would not even notice if they had an absence seizure. As Charlotte, Phoebe's Mum explained:

she wasn't aware of anything going on, you know, she'd be reading a book and she'd read a couple of sentences and just stop, and then she'd go 'oh right okay' and start reading again and totally unaware, she just stopped.

This lack of awareness of an absence seizure occur naturally means that any involvement in this aspect would be impossible for children. The differing types of seizures can consequently influence how involved children can be in this aspect of their epilepsy.

As shown, children can be and are actively involved in their management of seizures, indicating agentic action, sense of responsibility and competency. The active involvement of children is also seen from their parents' perspectives to varying degrees. Children's involvement and responsibilities in this management is seen through their appreciation of risks and their roles in the 'plans' they have developed with parents on what to do should a seizure happen. Their ability to tell parents about their seizure is mediated by the type of seizure they experience and whether they experience auras.

5. Summary

In summary, this chapter has explored children and parents' roles, responsibilities and connected involvement in the treatment and management of their childhood epilepsy. Regarding treatment, most children spoke at length of their self-assigned responsibility of remembering and taking their medication, with parents administering the dosage. Although some children stated feeling able to administer their own medication, the majority still preferred their parents maintaining this responsibility, due to the perceived danger or a lack of interest on their part (Prout et al, 1999). For parents, the treatment regime was their ultimate responsibility; ensuring their child remained 'safe' and took their medication, often crafting strategies to make

it as acceptable as possible. Children's agentic contributions in their treatments were consequently often not realised by parents (Wyness, 2013); this was particularly apparent around taking medication.

Similar findings were seen regarding the management of seizures. Children's self-defined responsibilities in keeping themselves safe were acknowledged to an extent by parents, although not to the shared degree which children reflected. Parents' reflected an invitation for children to be agentic through ensuring they knew what to do in event of a seizure, mitigating the potential risk they felt as discussed in the previous chapter (5). The use of material resources, such as mobile phones and friends, enabled parents to feel able to encourage and trust children's involvement, facilitating and encouraging children's agentic contributions (Kirk, 2010; Wyness, 2015). The level of understanding and knowledge of medication and seizures did not necessarily correlate with children's quests or acceptance of involvement or their autonomy around responsibilities to risk (Bluebond-Langer and Korbin, 2007).

Across the findings, children's potential as agentic actors' was primarily contingent on parents appreciating and encouraging it across these dimensions (Christensen, 1998; Moran-Ellis, 2013). The moral imperative and felt responsibility to keep their child safe, replicated across this chapter and the previous (5), 'thinned' any potential agentic opportunities (Klocker, 2007; Wyness, 2015). The next chapter will explore children and parents' experiences and involvement in a clinical context.

Chapter Seven: Experiences and Involvement in the Epilepsy Clinic

1. Introduction

The last two chapters (5 and 6) discussed how children and parents experience and are involved in the treatment and management of childhood epilepsy in an everyday context. This chapter will continue exploring experiences and involvement, this time in the clinical context of a routine epilepsy clinic appointment. Many decisions and discussions regarding treatments and management of childhood epilepsy take place in clinical settings with healthcare professionals. In them, treatment regimes and management approaches can be created and altered, affecting how children and parents experience epilepsy in the everyday context. Connected, the clinical context is a further area in which to explore children's involvement and agentic activities, drawing on the themes of agency from previous chapters.

As detailed in the methodology chapter (3), the clinic appointments form a standard part of paediatric epilepsy care in South-East Scotland. They serve as 'check-ups' to ensure treatment regimes are working effectively and provide an opportunity for children and parents to discuss any issues or concerns they have regarding the regimes, and epilepsy more generally. The appointments I observed were usually led by paediatric neurology consultants and epilepsy specialist nurses and held in various clinical facilities. Due to the geographical spread of the children and parents involved in the study, I visited three different clinical sites: a children's hospital, a district general hospital and a small community hospital. I observed one clinic appointment for twenty children (there was an attrition of three since the first interview, as discussed in chapter 3).

This chapter presents data from these observations and a second interview which was carried out after the appointment. Just before, during and immediately after the appointment, I quietly observed the context, the interactions, presentations, and questioning occurring. These observations created and assembled an account of the appointments to better inform discussions in the second interview as well as providing a descriptive context of the conversations. To further aid discussions in the second interview, 'pots and beans', a ranking exercise was used. This tool enabled an

interactive means of discussing different aspects of involvement in the appointment. A more in-depth discussion and reflection of this tool can be found in chapter 3.

This chapter explores the experiences of attending clinical appointments by reflecting on children's and parents' time in the clinic and the appointment. First, the moments before an appointment will be detailed, elucidating the preparations drawn upon, who attends and the environment in which the clinics are held. Secondly, what happens during the appointments will then be explored using both observational data and children and parents' reflections obtained through their respective second interviews. In particular, the moments of involvement for each individual present will be highlighted, closely examining how children and parents experience and manage these moments with healthcare professionals and the decisions that can emerge from them. I will also connect these moments of involvement to agentic potential and realisation, exploring how the clinical context can facilitate and constrain. Finally, what happened straight after the appointments will be reflected upon before the chapter concludes with a summary of the main findings.

2. Before the Appointment

The time before a clinic appointment will now be examined. Six children said during their interviews that they had spoken in advance to their parents about the appointment. For example, Abby, reflected that "*We chat about... about what we want to talk about in the appointment*", while Craig recalled speaking to his Mum, "*about, like, am I going to come off them [medication] after the summer holidays*". In both instances, parents were presented as encouraging Abby and Craig to think about the appointment coming and what might be discussed. As Charlotte, Phoebe's Mum, reflected on these types of conversations before appointments:

Just briefly, you know, to remind her that we were coming and just what's likely to be said because, you know, there was nothing particularly important...

Similarly, Shirley, Abby's Mum, reflected:

I just said to Abby, did she have a wee thing in particular she might want to ask cause, you know, it's always useful to know that so that you can remind her cause when you're in an appointment you forget.

Pre-clinic conversations can be a means of getting children to think about what might happen and advising them of potential decisions and topics of importance that may be discussed during the appointment, thereby enhancing children's involvement in the clinical encounter. These conversations can be seen as a form of preparation for the upcoming clinic appointment with children, perhaps illustrating a means of facilitating their agentic potential and the shared nature of attending clinics for them and their parents.

Anticipatory engagement with the appointment was not always undertaken, or viewed as desirable, however, with four children explicitly stating that they did not want to discuss the appointment beforehand with their parents. Three of those children did not wish to explain why, simply shrugging in response. Maisie appeared initially reluctant to explicate further, but her Mum interjected to suggest: "*was it cus you thought you were going to get into trouble for not taking medicine maybe?*" – to which Maisie responded, "*erm, yeah*". Such comments are suggestive of the ways in which anticipatory engagement can provide a discursive area for playing out ongoing discussions about living with epilepsy which children, and parents, may wish to avoid; hence, the possibility is closed off through ceasing to discuss the appointment beforehand.

Ten children did not recall discussing the appointment in advance. Esther explained: "*I don't need to. I know what's going to happen, been to a million of these*", illustrating how normal the appointments were to her. Likewise, three parents reflected that they also did not speak to their child in advance of the appointment; as Eric, Esther's Dad, mirrored his daughter: "*No because I think she's been in so many I don't think there was any... I don't think we were expecting anything unusual*". Similarly, Jane, Susanne's Mum stated, "*it isn't really necessary. I don't think*". The regularity of the appointments and the standardised content meant that attendance was routine for these parents, and thus without requirements for special preparations.

Despite the limited discussion in advance of appointments between children and parents, more discussions took place between parents. This would primarily occur when only one parent could attend the appointment. For instance, John, Nicola's Dad, recalled: "*we obviously we discussed whether she was going to stay on that medicine or what not, so I know [Shona, Nicola's Mum] had asked me to find out*". In this

situation the potential discussion around medication changes had already been anticipated and spoken about by Nicola's parents. Other parents acted similarly: Iain's Dad stated that "*we speak about it all the time*", whilst Wayne's Dad, Alf noted: "*we have chats all the time about it*". Such assertions present a united approach to decision-making and agency around treatment and management, with the phrasing "*all the time*" alluding perhaps to their ongoing nature (i.e., not just when something happens or before appointments).

3. Entering the Clinic

Despite 'the' clinic being held at three different locations, each site had very similar waiting areas. Plastic chairs were placed in rows along a corridor, with a separate area with some toys, books, and colouring-in pens. In one location, two computers were also available for children and young people to play a small number of games. There was minimal decoration, with the walls adorned with health promotion and educational posters and messages. These areas were nearly always busy, noisy and warm. As Courtney described: "*it's so noisy there*" and Alex mentioned, "*that bit goes sooo hot*". These areas were seen purely as places to wait in, as Wayne's Dad, Alf described, "*a waiting area's a waiting area sort of thing*".

In reflecting on their own attendance at the appointment, which although not mandatory was heavily inferred, twelve of the twenty children felt that their attendance at the appointment was important. This was primarily "*because it's my appointment*" (Susanne), and similarly as David stated it was, "*because I'm the one that has the seizures*". The reflections that it was '*their*' appointment appeared fundamental to these children's conceptualisation of the appointment and its value to them, adding a sense of ownership. As Phoebe added, "*I think it's important for me to know about my epilepsy and how I'm getting on and stuff*". Such statements indicate how engaged children are with their epilepsy treatment and management, their quests to understand, and the value they place on interactions with the healthcare professionals. All displays of agency.

Children were always accompanied by one or both of their parents to the appointments. Which parent attended depended on work schedules and availability, all of the appointments happened during the school and working day. Parents'

presence at the appointment was seen as important for all twenty children. As Yasmin reflected: "*he [Dad] is always there which is good*". Phoebe also spoke about her Mum attending:

Phoebe: I'm glad my Mum was there.
Int: Yeah? ... Is there a time when you think your Mum shouldn't be there?
Phoebe: No I'd never want that. She should come.

Their parent's presence was seen as valuable. It was also seen as natural: "*I found it alright, it was normal that they were in as well*" as Wayne described. When asked whether they would want to go to the appointment alone, 17 of the children responded, as Phoebe did, with a resounding '*no*'. However, the roles parents had within the appointment varied, as will be illustrated in the next section examining the happenings of the appointment.

Three children, though, did allude to some hesitancy with their parent's presence in the appointment. Emma reflected on her Dad's attendance: "*he needs to be there so that he can know how my health's going [laugh] but he could be, like, he does sort of sit very quietly and listen, but his opinion is valued*". For Emma, her Dad's presence was not necessarily for her but rather for his own informational purposes so he was aware of what was happening with her. Emma also alluded that her Dad did not necessarily need to participate in the appointment, though his '*opinion is valued*' by her. Likewise, Esther reflected: "*Yeah cause it's good they give their opinion*" when asked whether her parents should attend the appointment. Again, this suggested that parents' attending their appointment was acceptable, but their presence was more to keep themselves informed and involved, rather than for potential support for Esther. Jack was the only child to state: "*I would rather she didn't come in*"; hence, in spite of the clear majority of children wanting their parents present in appointments, this cannot be taken for granted. Notably, these three children were seen by clinicians as highly involved and engaged in their appointments demonstrating agentic action, as will be illustrated in the next section of the chapter.

Whilst waiting for their appointments, the majority of children and parents sat together. Three children focused on other activities, namely colouring-in (Maisie) and playing on the computer (Rosie and Mike), leaving their parents sat close by. None of

my participants interacted with the other children or adults waiting around them. My presence possibly altered how this 'before the appointment' time was experienced by children and parents. Conversations between children, parents and I occurred, usually about what had been happening since I last interviewed them, including recent health issues (e.g. broken bones, not related to epilepsy), holidays, and happenings at school. These conversations tended to be driven by parents and were perhaps attempts to make conversation and to tell me what had been happening in their lives. There were only two instances where the upcoming appointment was discussed in this 'before' time: Christine, Lily's Mum, asked her elder daughter to remind her in the appointment to query with the doctor about how Lily had been feeling lately, and Wayne's family spoke about his epilepsy with regards to some recent school absences.

When I asked the children to reflect on the time before their appointment, nearly all spoke about feeling – in Phoebe's words – "*a little bit nervous*". Craig expanded: "*A teensie bit nervous... Just about what they were going to say and stuff*". As Cathy, Melanie's Mum, reflected, "*it's the type of setting I suppose, it's slightly alien*", the environment of the appointment can add to the nervousness and anxiety most children reflected experiencing in advance of their appointment. Recognising his nervousness, Wayne also spoke about how he managed this:

Quite nervous but once I had got going, I felt it's fine. I'm just going for a check-up, he's not going to do anything, he's just going to ask me questions like what you're doing, cause you're asking questions about epilepsy and that's just what he's doing.

Such an approach is illustrative of preparatory processes and shows how children deploy agency and engage in the process despite professed nerves. Maisie also spoke about a strategy for managing anxiety, "*I was thinking about it a lot and then the drawing kinda took it off my mind*". The provision of colouring-in materials in the waiting area thus apparently benefited Maisie.

Parents also sought to reassure their child before appointments, as Monica, Courtney's Mum, said:

I told her that [the appointment] was about her epilepsy this time and that you [researcher] were going to be there and obviously she had the bit worry that

it was going to bring on a seizure and I was like 'well it's not going to, you'll be fine'.

The offering of reassurance that the nothing 'bad' would happen, was also reflected by Jean, Iain's Mum, who stated: "*oh we always have to reassure him that he won't be kept in overnight, bless*". Parents offer these statements to mitigate any potential distress for their children and to ensure attending the appointment went well.

Waiting for appointments to start was described by parents as intensifying the anxiety and nerves their children experienced. All bar three of the appointments that I observed ran late, irrespective of the appointment location or time. Wendy, Mike's Mum noted that "*we are sitting a long time... Quite a few times*", suggesting that such lateness was not coincidental. This appeared to be part of the routine of the clinic for some participants; even though Rosie's appointment ran 25 minutes late, her Dad reflected: "*there has been sorta times when we wait half an hour or 45 minutes or something. But it was a lot quieter today which was not normal*". Such waiting had implications for other aspects of parents and children's lives, including: childcare for other children, parking expenses, and attempts to return to work and school following the appointment. During the wait, six children became visibly more anxious and agitated, with three asking at this point of the observation if they could leave, adding that they had waited long enough. Only three consultants apologised for running late when meeting children and parents for the appointment, with a number of parents passing comment about this to me after the appointment.

In sum, before the appointment it has been shown that children and parents can have implicit and explicit expectations when arriving at the clinic. These expectations develop through the routines of attending. These moments before an appointment can provide the opening and opportunity to encourage and enhance children's agency and involvement in their appointment and the wider treatment and management discussions (Curtis-Tyler, 2015). In this sense, the appointments can be seen to become shared encounters with healthcare professionals for children and parents (Tates and Meeusesen, 2001; Ruland et al, 2008). However, the anticipation of how the appointment will unfold and the lack of influence over how long they will be made to wait, can all discourage and cause anxiety for children, potentially constraining their agentic potential.

4. The Appointment

All the appointments were conducted in similar rooms across the three different sites, though they varied in size considerably (with the smallest in the community hospital). The rooms were standard outpatient clinic rooms, which could also be used for clinical practice when overflow space was required. There was always a computer and desk in each, which appeared to be the focal point of the room with an assortment of plastic chairs arranged around it. In all cases, a hospital bed and a sink with various brightly coloured soap dispensers was present, and sometimes other clinical equipment - emphasising the versatility of the rooms. Most parents and children did not particularly reflect on the room and the atmosphere it created; as Sharon, Maisie's Mum, reflected, "*it's a hospital room, ain't much more to it*". Likewise, Marcus, Alex's Dad, stated: "*yeah, suppose it does its job*". The rooms, consequentially, were regarded as functional, serving their purpose as arenas within which children, their parents, and clinicians could meet and discuss epilepsy.

A handful of parents and children contemplated the room in more depth, however. Uneasy feelings were seen by six children; for example, David stated "*it's not nice... not very you know... relaxing*" and Jack: "*it's like visiting the head teacher*". These references suggest the rooms and the environment are failing to foster a warm and welcoming situation in which to feel able to participate comfortably. Three further notable examples of such feelings included Phoebe's observation: "*There was an electric thing that I didn't really like... A little bit scary, like, it could really hurt people*". Her observation of a piece of medical equipment in the room, an ECG machine, brings to attention how children can, and do, absorb details about the room and how this can shape their experience. Similarly, in Esther's and Wayne's accounts, both children spoke about the '*dead bodies*' that could have been in the room with them or in the hospital more generally. For example, Wayne described:

Wayne: *Makes you feel a bit oooh, cause there might be dead bodies in it.*
Robyn [Mum]: *Not in a hospital room, I wouldn't like to think so!*
Wayne: *But some people can die in a hospital.*

Associations of hospitals and death could be influential in how comfortable and safe children feel about these appointments: Iain added, "*I'm ok as long as I don't have to stay in longer*".

Considering the environment, Ellen, Philip's Mum, reflected that it was "very empty and clinical and strange for a kiddie's place". Reinforcing this, Colleen, David's Mum, also noted: "the room is not the best is it... It is similar to one he was rushed into after the seizure...". This similarity in room has emphasised a 'clinical' feel to the room, potentially bringing back memories and feelings of times when children have had to attend hospital in emergencies. Furthermore, while the room and the presence of the medical equipment or clinically relevant materials might be familiar to children and parents, it also serves as a constant reminder of the quintessentially *medical* setting of the appointment, with all the (positive and negative) cultural and emotional associations that entails.

Two teams of healthcare practitioners led all the epilepsy clinics across the three sites. These teams involved six paediatric neurologist consultants and three Epilepsy Specialist Nurses (ESNs), who worked together during clinic appointments and the broader paediatric neurology service. Although, two lead consultants ran the clinics, each appointment was facilitated by a different consultant and or ESN depending on who was available. This collaborative approach meant that children were not necessarily seen by the same healthcare professional at every clinic appointment in the urban site. Due to reduced staff and patient number, the same consultant and ESN led most of the appointments in the two more rural sites.

Ten parents reflected on this collaborative approach to facilitating appointments. Derek (Iain's Dad) considered:

I think in all the appointments we've had, on every bit of paper it's got [consultant]'s name on it and all the times we've come here we've maybe seen [consultant] twice, so it's not a moan, it's not a grumble... but I think I would... makes me feel better...

Emma's parents (Julianne and Ryan) also spoke about meeting different healthcare professionals at Emma's appointments:

*Julianne: they don't always agree with each other.
Ryan: Yeah, it's very strange. Well the vitamins is a great examples cause is it [consultant] is that right? He prescribed them because she had sort of achy bones and he says that sometimes they have observed a Vitamin B deficiency in children with epilepsy, so this is why he prescribed it. But then we saw*

another consultant who seemed to think that that was not really founded and was probably just growing pains, which it may well be I don't know, but it's interesting that there seemed to be different opinions.

Such comments are suggestive of unease about seeing different practitioners who may have diverging views and opinions, in situations where clarity and trust are central. Similarly, Sharon, Maisie's Mum explained: "*if she'd got some more issues I would want to speak to the same doctor*", emphasising a potential need for consistency and familiarity in more complex clinical situations/cases.

This preference for the same doctor was not expressed to the same degree or in the same ways by all parents, however. Prioritising her child's feelings over her own, Shirley (Abby's Mum) reflected:

I wasn't too phased, you know, about it being somebody different although I wondered if the kids would be because, you know, when you go sort of thinking they might see somebody and it's not.

John, Nicola's Dad put it plainly: "*seeing someone different doesn't really make a difference to be honest*".

Most children did not discuss in detail what it was like to see a different healthcare practitioner, with many just stating it was 'fine'. Only a handful of children explicitly mentioned some discomfort; for example, Iain reflected: "*I didn't really know the person that I was chatting to the most*". This seems to suggest a potential unease experienced by children when speaking with an unfamiliar healthcare practitioner.

In thirteen observed appointments, an ESN attended in addition to a consultant. The presence of the ESN was welcomed by children and parents. For example, Colleen, David's Mum, stated:

When [ESN]'s in it's not as quiet but I think that's their demeanour and the doctors got a different way of talking to the kids than them, and I think I find it difficult when they aren't there.

Likewise, for Lee, Craig's Dad, this benefit comprised of the ESN acting as "*a buffer between the doctor and...the parent*", since they "*take the time to chat to you about*

things". Children also reflected similar feelings of benefit and understanding; Maisie, for example, described: "*she's [ESN] nice [...] yeah its better when she's there too. She is better to listen to*". The difference noted, through their interviews, by parents and children in appointments when ESN's are present, illustrated a benefit these professionals provide to the appointment.

Two appointments observed were led by only an ESN, with no consultant present. The parents attending those appointments expressed disquiet about the absence of a consultant, with Derek, Iain's Dad stating: "*I didn't expect to see [ESN], I expected to see one of the consultants*". After initially asking what the difference between a consultant and an ESN were, he reflected:

that's why I was asking what the difference is between a consultant and nurse, makes me feel, I think that [consultant] knows more and is able to give us other options or perhaps a better diagnosis of what Iain's going through at the moment, but that's not anything against [ESN].

Derek has questioned whether the ESN can provide the level of medical insight and support that he feels was needed for Iain's treatment, causing a sense of worry and concern. This illustrates that although ESNs are viewed as valuable additions to appointments, they are not considered equivalent to consultants in terms of treatment provision and management guidance. The expertise of ESN's is generally constructed as relating to the facilitation of medical guidance and supervision, such as acting as a 'buffer' or 'listening' to parents, rather than directly deploying medical knowledge themselves.

Despite the different practitioners leading the appointments, all the appointments observed began in the same vein. The practitioner called the child and their parent(s) through to the room and directed them to take a seat. The lead healthcare practitioner was always sat near or behind the desk with the computer. If other professionals were in the room, they would opt to sit near the leading professional and separate from the family. The welcoming to the room and the seating arrangements could be seen to set the tone of the appointment, with the healthcare professional in charge with their seat at the desk emphasising their status in the appointment and families placed opposite, on the plastic chairs.

A handful of children reflected on where they chose to sit during their interviews; for example, Mike reflected: "*I just chose the one at the end, I usually sit in the one at the end. By the doctor*". David was less particular, stating, "*I just pick any*". For some children, when the seat they ordinarily picked was altered, this caused concern. As Lily mentioned: "*I didn't get why I couldn't sit there*". Equally, David's Mum, Colleen, stated:

the doctor ask him to switch seats, because when we went in David went in in front of me and he automatically went for the seat far away from the desk and the doctor asked him to switch and I think that really kinda threw [David].

Although which seat to sit in was not considered significant by the children I interviewed, the ability to actively select their seat nevertheless was important. This could be seen as a way for children to exert their control (and agency) in what could be felt to be an unnerving environment, causing further discomfort when told they must sit somewhere else.

After arriving in the room and taking their seats, the healthcare professionals began the conversations with an open and broad question such as '*how are things?*' or '*how have you been?*'. A range of discussions then took place, including children's wellbeing, recent or latest seizures, current progress at school, and medication taking and changes to medication. These conversations were nearly always initiated by healthcare professionals, and directed to parents using, often the same questions observed across the different appointments. The questions asked and the discussions initiated reflected the need for healthcare practitioners to capture information to assess how a child's treatment and epilepsy management was progressing. This need to elicit information was considered by children to be important to the appointment and to the discussions had. For example, as David reflected: "*all that happened was... he was asking, like, a tonne of questions*" and Alex's thoughts: "*they are all about just asking how I am and stuff... asking questions and stuff*". The constant concern for '*what's happening*' was seen as the primary reason for the appointment, and in children's views, the role of for the practitioners, specifically consultants', to '*find out*'. As, Emma explained: "*Because he's the consultant and he had to tell me what was going on in my brain and he had to ask questions as well*". Rosie also added: "*the doctor he knows what's happening and he knows stuff*". The recognition of the doctors' expertise and their role in providing treatment regimes underpinned

children's perceptions of the important role healthcare professionals have in the appointments.

As previously shown, the setting of the appointments can provide an uncomfortable and unsettling environment. Despite this, the format of the appointment (observed) and the questions asked were seen to most children and parents to be the same, as Susanne reflected for example: "*well it was like normal*", and Marcus, Alex's Dad, said, "*yeah standard questions, the usual*". Consequentially, this creates a sense of familiarity regarding the appointment, and the interactions within them. The roles children and parents create and negotiate in these appointments will now be explored alongside potential complications to children navigating and enacting their own involvement.

4.1 Involvement: Roles and Obstacles

4.1.1. Roles

Most children reported that contributions to the appointment should be shared with their parent(s), reinforcing the notion that appointments can form a shared endeavour and asserting autonomy. As Melanie put it, "*Me and my Mum did it together*". Similarly, Abby explained: "*I need to answer them and Mum needs to answer them*". This collaborative approach to answering questions and contributing to the appointment can be seen to share the burden and responsibility of imparting the information needed. Abby, though, specified that "*Mum answered adult stuff. I did the kid stuff*". A similar segregation of the topics and questions answered by children and parents was described by Susanne: "*Mum does the serious stuff. Adult stuff. I do the non-serious stuff [laugh]*". This sharing and apportioning of the questions illustrates the level of involvement that these children wish to have during the appointment and indicates the types of conversations children wish to be involved in.

Despite preferring and assuming a shared role, most children still reflected on their own contributions to the discussion as well. For example, Melanie stated that she spoke "*about things I was doing and erm if I was alright and any problems and things I had. So not much*". Courtney similarly talked about: "*my medicines and er... how I am and... stuff*". The contributions from children mainly focused on their own wellbeing and how their medication taking was going. These children did not reflect

any other contributions, such as around discussions on their seizure activity. In reflecting further on their involvement, a few children accounted for the limits they referred to; Susanne, for example, when asked why she didn't want to talk in appointments stated: *"I am shy that's why"*.

A minority of children presented themselves as considerably involved in the appointment. These five children described talking about and contributing to a range of topics with the practitioner. Rosie recalled:

I spoke what happened when I had my last seizure and the doctor he said 'what are you getting stuck on at school?' and I said maths and when the doctor said has anything been happening?' I said I had a tiny bit of a seizure.

All of these children spoke about being able to contribute to their appointments by answering questions and talking generally: *"I was answering questions"* (Emma) and *"I did the answering"* (Jack). Jack went on to add that his contribution was *"just the usual amount"*. One respondent, Wayne, alluded to perhaps talking too much, describing himself as *"a chatterbox"*.

These children also asked questions within the appointment - and asserted that it was important that they did so. Emma, for instance, stated, *"I think I'd probably ask it anyway because I don't want to, like, leave a question unsaid, you know, like, if I think something's bothering me I should probably say it"*. Similarly for Esther:

Int: ...what kind of questions did you ask?
Esther: If I was ever going to get my shunts removed and, yeah.
Int: So is that an important question for you?
Esther: Yeah cause I'm bored of them and they're annoying.

Question-asking thus linked to matters of personal salience to the children. However, articulating questions was not always easy: as Wayne explained, *"it was a bit nerve-racking to ask it"*.

Asking questions was not necessarily a useful appraisal of involvement. Craig asserted that there was no need to ask questions, when I asked if there was a reason why he hadn't asked questions, stating, *"the doctor really said all the answers to my questions"*

while she was talking". Likewise, Rosie replied: "*I didn't have any. He answered all my questions before I even had to say them!*". Such sentiments were seen across a further four children's accounts. This reveals that as an aspect of involvement, asking questions, could be overlooked or interpreted by others in the appointment as not being engaged in what is being discussed or their treatment regimes, when simply all the questions had already been answered.

Through the observed clinic appointments, these five children appeared confident and were actively involved in contributing to it. Emma, for example, responded to most of the clinician's questions, including those initially directed to her Dad. Throughout the appointment, Emma provided her opinion and thoughts on the topics being discussed, such as on the continuation of her medication treatment regime. The observations for the five children illustrated active and unprompted participation in their appointments, potentially illustrating their autonomous agentic involvement.

The active involvement, and consequential autonomy, of these children could be seen to be supported and appreciated to differing extents by their parents and healthcare professionals. For Emma, the consultant quickly seemed to realise in the appointment that she was comfortable answering questions and contributing positively to the discussion; thereafter, the clinician directed more questions towards her and explicitly sought her thoughts. Additionally, in an interview with Ryan, Emma's Dad, he reflected on his daughter's involvement:

I think she found it fine, she speaks well with adults generally speaking. I think over the years of coming to these appointments she's maybe become more accustomed to it and therefore more confident. So we are happy to let her just go for it [laughs] sit back and relax!

Both Emma's consultant and Dad have recognised her as an agentic actor and participatory role in this context and are supporting her by facilitating this involvement through their encouragement of her autonomy.

Support and encouragement from parents and clinicians was evident in six other children's accounts. For example, when reflecting on a decision to stop his treatment regime, Craig felt that it was "*probably me*" who made it. When I asked Craig why he made the decision, he replied:

because, like, it's me who has it, I know how I feel and I feel very confident to go off them because I don't feel like I'm going to have one that much.

Here, Craig accounted for the importance of his involvement in clinical decision-making, demonstrating his felt autonomy and competency. As we discussed this decision further, Craig added that he felt it was "frightening" to make it himself, but that the doctor and his parents "helped me understand what I was going to do, like, what was going to happen maybe". In this way, Craig's Mum, Annie and the consultant are constructed as enablers of his agency. In discussing Craig's involvement in this decision, his Mum reflected: "We have spoken about it a lot with him over the recent weeks. He knew it was coming. He knew they would ask". Anticipatory engagement with the appointment themes is thus apparent, facilitating Craig's agentic potential within the clinic. This further demonstrates the potential scope for involving parents, creating opportunities for children to be agentic actors.

Similarly, in discussing the decision to be discharged from the epilepsy clinic:

*Jack: The doctor with a bit of influence by me.
Int: Yeah?
Jack: And a tiny bit from my Mum.
Int: So what kind of influence did you think you had in the decision?
Jack: Because it was my body, I got to decide what I would like to do with it.*

Jack was certain of his decision and that, although the doctor made the decision, it was with his influence. Underscoring that the decision was about him and his body emphasised the important role he felt he necessarily had in the decision.

However, Judy's (Jack's Mum) recollections of the encounter revealed a different perspective on this decision-making process:

it kinda went the way I expected it to go. I thought that's what would happen and I thought the doctor handled it reasonable well because he got him to make a decision almost as well, you know, it had to come from him too, so no I think that was fine yeah.

Judy's reflection suggests that it was the doctor who had made the decision to discharge Jack initially but that the decision-making process had been structured in a

way to involve him. This suggests that feelings of agency are possible to cultivate in the absence of clear autonomy.

Similar to this, Wayne's Dad, Alf reflected on his son's contributions to the appointment: "*I think it's important to always make the child feel that they're involved, I mean, he was waffling on quite a lot about things and I kinda thought 'what are you talking about?'*". Wayne's Dad, Alf seems to be suggesting that Wayne's contribution was always facilitated and welcomed, but nevertheless that it was not always insightful or valuable in relation to the overall discussion; in effect, Wayne had apparently not yet learned the discursive rules of the quasi-scripted clinical encounter. Both reflections are suggestive of a sense of artificiality to their child's involvement in the appointment: children are involved in the appointment because they must be, but their contributions are not necessarily deemed of instrumental value by parents.

A further example of this valuation of children's contributions was reflected through fourteen of the observed appointments. In these, healthcare professionals would frequently ask the child a question - for example '*how's your medication been going?*' - and after hearing the child's response, would either ask the parent attending the same question or would then look to the parent for confirmation of the child's answer. This repetition of asking the same questions and checking answers could be felt as diminishing; minimising the contributions provided by children and consequentially their agentic opportunity. This situation more frequently happened when children were not sure or did not correctly identify/recall the name and dosage of their medication, reiterating the previous assumption that level of medical knowledge was associated with a child's engagement with wider aspects of their condition (see chapter 4).

The perception of children's involvement can differ between children and parents. Judy, Jack's Mum, for example, reflected on Jack's involvement in the appointment: "*I was kind of hoping he'd say a bit more himself, I tried to say very little but occasionally you have to prompt a wee bit*". From Judy's perspective, Jack was seen to be minimally involved and required pushing to participate in the appointment. This, however, contradicts with Jack's own reflections on his own felt involvement. Jack stated that he "*did the answering*" of the questions, adding: "*well apart from the ones that Mum spoke. She answered some of mine*". Jack's reflection suggests that he feels he

contributes greatly in answering questions and has even more to contribute but that his Mum hampers his involvement by answering 'his' questions. Through the observation, it became apparent that Jack was getting frustrated at his Mum interrupting and adding her own thoughts to the conversation. These differences in perspectives illustrate how different involvement can be perceived as well as the importance of gaining multiple perspectives. It also reveals how challenging it can be to recognise children's involvement and their agentic potential by others in such clinical settings.

Only four children stated their complete disinterest in being involved or to contributing in the appointment. Nicola, for example, reflected: "*I just have wee daydreams while I am there*". Similarly, Yasmin specified that she did not wish to talk to the doctor about her epilepsy at all, stating that she spoke: "*yeah, not much. That's how I like it*". Yasmin later added that she would perhaps think about being more involved, "*when I'm older [...] kind of like 15, a bit older*". Until then, she would rather her Dad spoke the most in the appointment. Both Nicola and Yasmin have agentially asserted that they chose *not* to be involved and by leaving their parents to manage the appointment.

Yasmin and Nicola's lack of interest in being involved in the appointment prompted different reactions by their parents. John, Nicola's Dad reflected:

she just hates talking about these things and in the appointment [...] She understands what's going on, she knows a bit about it all, but we try and explain it to her but she's, she's... Yeah I don't think she wants to know too much to be honest.

John seems to accept and understand Nicola's active withdrawal and disinterest, later adding: "*she's still young*", perhaps alluding further to why they have accepted her desired limited involvement.

In contrast, Ash, Yasmin's Dad had hoped Yasmin would be more involved and engaged:

when I came here then I told her 'you have to speak up this time' Yasmin [...] but we were chatting she never talked [laugh] she kept quiet. Especially as

Yasmin get older you are to speak up more. I don't know if she's nervous or anything when she go there.

Though recognising that Yasmin may get nervous when she gets there, Ash identifies the connection between Yasmin's age and the enhancement of her competence and perception of her agentic capacity, indicating that further involvement in the appointment will be necessary as she gets older.

Eight children who self-described as minimally involved, suggested that they perhaps 'should' be more involved in their appointment. For example, in response to a query about whether she should answer more questions in the appointment, Lily said: "*yeah I should... kind of*". Likewise, Courtney noted, "*I should talk more*", and Susanne explained: "*I should maybe... I don't know... it is my appointment*". The repetition of 'should' illustrates a sense of obligation children felt to participate in their appointment. However, this sense of obligation was not universal amongst children who were minimally involved; as Abby reflected: "*No, I don't want to. Mum should do the talking*". Abby's statement illustrates her preference would be to speak less as oppose to more. Consequentially, she rejected involvement in the appointment, demonstrating agency through passive and uninvolved actions.

In reflecting on their role as parents in the appointment, twelve of my adult respondents felt communication was one of the key aspects of this. This included being the one to talk to the doctor or provide the information on seizures and medication taking. For example, Derek, Iain's Dad, explained:

I try to let Iain speak for himself but... it's just for me to tell the absolute truth about everything that he goes through, not hold anything back, just to tell them everything that I think they might need to know in order for them to make him better.

This illustrates his role in the appointment in conjunction with the sense of responsibility this role brings in the appointment. Further, Derek appears to suggest that he is able to provide a full and truthful account of Iain's epilepsy, beyond what Iain himself could manage. This reflecting how he views his son's competence and ability to provide such an account.

For three parents, this communicator role meant being the 'voice' of their child. Monica, Courtney's Mum, stated:

Well Courtney doesn't talk a lot so I tend to have to do a lot of the speaking for her, you know, I do worry about the time she has to go in herself, she doesn't talk much but a lot of the time I just pass on what's happened cause she doesn't [laugh]! I'm her voice.

Likewise, Sharon, Maisie's Mum added: "*I think, well obviously to speak to, well for Maisie, I find that it is answering for Maisie rather than Maisie answering*". This view of leading the communication was primarily seen in parents whose children felt less involved in the appointment.

For twelve children, their parents' contributions to the conversation and answering questions was presented as an important aspect of their parental role in the appointment. For example, Nicola reflected that her Dad spoke about:

*Nicola: Important stuff.
Int: Yeah, what kind of important stuff? ... Can you remember anything in particular?
Nicola: About me*

Similarly, Courtney said that her Mum spoke about "*what happened during the fit*", which was "*a good thing*". Additionally, Alex reflected: "*that's what he's [Dad] there for*" and, as Philip stated: "*they [parents] talk about me and my epilepsy [Int: Is that a good thing?] yeah of course*". These aspects of contribution were seen as invaluable and about them and their epilepsy. For these children, talking and providing information during the appointment was a significant part of their perceived role as parents to children.

Alongside answering questions, directing queries back to the clinician was also indicated by the children to be important. As Craig stated regarding his Mum asking questions: "*Yeah, like, because she watches out for me, like, keeps an eye on me on, like, behaving and doing*". Susanne explained that her Mum "*asks important questions [...] like erm, how long erm, how long will I have to stay on the medication for and when I can stop and stuff like that*". The questions were always about the children; as Lily put it: "*about me*". The focus of the questions reiterates children's perceptions of their parent's role to look after children and their best interests.

A further key component of parents' role was to ensure that their child felt supported in the situation. Wendy, Mike's Mum stated: "*I suppose I'm just there to support Mike*"; similarly, Marcus, Alex's Dad, responded that his role was "*to be there*". This role of support was summarised as 'being a parent'; as Derek, Iain's Dad reflected: "*My role's just to be... be a Dad*". This support was primarily viewed by children as their parent being present (as detailed in the first section of the chapter), but also as a form of translator. David described this as follows: "*if [consultant] says it in a different way, like, a different word from what I know, Mum would tell me what the word is*".

The roles each individual hold in the appointment has been established by children: healthcare professionals question and interrogate, whilst parents communicate updates and problems. Children themselves self-identify a role within this, presenting themselves as agentic actors, yet their contribution in this setting can be seen to be facilitated and managed by the adults present (Coyne, 2006; Deddings et al, 2014). The quality of facilitation can however create obstacles and barriers to children's agentic contributions; this will now be explored.

4.1.2. Obstacles

The roles children and others hold in the appointments can be changeable and dynamic. The thoughts and feelings children use to describe their involvement and contributions to the appointment reflect similar variability depending on different circumstances. Emma reflected on such shifts herself:

Emma: ... I didn't want to be the centre of attention because it's a little bit nerve wracking when you're being asked questions about yourself [laugh].
Int: Yeah so you were kinda glad that they asked your Dad?
Emma: Yeah but I find it better now for them to ask me because, like, I get to say what I think, yeah, I have more of an opinion now I think.

Emma's reflections illustrate changing feelings regarding involvement and being asked questions. Her nervousness could reflect how most children initially feel when attending the appointments, yet as Emma goes on to add, this may change over time. The challenge, for parents and healthcare practitioners, arises in understanding and establishing if, when and how these feelings occur. On reflecting this challenge, Emma added:

Yeah, sometimes I think that some people don't really like include me as much as they should, or like in the past they have. I think recently they've been, like, doing it more, think that might be because I'm, like, maybe a bit older, like, more able to understand.

Knowing whether a child wishes to be involved is, however, a challenge for parents and healthcare practitioners, and could cause a barrier for children wishing to be involved when their desires are overlooked. For example, Philip spoke about his attempts to be involved in his appointment:

Philip: I was trying to ... I tried to tell him [doctor] that I am getting better behaved than I previously was...

Int: ... Do you think he heard you when you were talking?

Philip: well I never actually erm got the word out because erm I was waiting for when it stopped, for when people had stopped talking for a minute but then of course others were starting again. I didn't want to interrupt.

Philip's minimal contributions to the appointment were, from his perspective, due to others in the appointment not providing him the opportunity to participate leaving him unable to speak. From the observation of the appointment, it was clear that Philip had something to say during a particular discussion regarding his school attendance and behaviour. At one point he raised his hand, appearing to try and get the attention of the healthcare professionals or his parents; this arm gesture is a common approach for children to use in schools where they are often required permission to speak (Mayall, 1998). In response to this, his Mum lowered his hand for him and leant in to him allowing him to whisper in her ear. There was no reaction from his Mum about what was said in this moment and nothing appeared to change in the appointment. Throughout the appointment more generally, Philip followed the conversation, listening to everything and tracking the conversations: it was apparent that he was absorbing everything, nodding at parts he agreed with. From the observation and Philip's own account, he was excluded from the conversations and no attempts were made to include him by either the healthcare professional or his parents. Rather than enabling his agentic potential, the clinical encounter and participants, instead served to constrain.

Another obstacle that can impact on children's potential to participate and enact their potential agency during the appointment was their understanding. Nearly all the children mentioned not understanding at least an aspect of the appointment. For

Courtney it was just "some bits", whilst Craig struggled with "just really the medication words, they're confusing". Similarly, David mentioned: "I dunno, I just... some of the words and stuff". They went on to explain how that "Like, makes me feel that I'm not very bright because I don't understand what it means". The additional reflection by David emphasises how a misunderstanding or not understanding something altogether can make children feel inadequate. David made a judgement that he was not smart and his medical understanding and knowledge was poor due to the consultant's use of words. This insight into how it makes David feel is valuable and can indicate a further potential obstacle for children to overcome in order to feel able to fully participate and be involved as agentic actors.

A handful of parents also reflected on a similar potential obstacle for children, sensing that on occasion, their child was confused by the questions asked of them in the appointment. For example, Wayne's Mum, Robyn felt that Wayne struggled to answer questions in the appointment because:

I don't think he knows what to say because it doesn't really affect his day to day [...] I think he's maybe a little bit overwhelmed sometimes when he goes in cause he's not quite sure, doesn't know what to say... he's probably panicking, 'what is the right answer, what do you want me to say?' I think he's at that kinda age, eager to please and wants to say the right thing and do the right thing.

Wayne's lack of understanding of the medical aspects of his epilepsy could be influencing his actual and potential contributions to the appointment. Furthermore, Colleen, David's Mum, reflected: "I thought some of his [doctors] questions were a bit mmm, I'm not really sure if they were good or if David understood them". The querying of the line of questioning also raises concern to Colleen and reiterates the wider concern about children struggling to grasp the questions they are being asked. This could potentially be an obstacle for children. Their understanding, knowledge, and frames of reference around epilepsy may be different to those of healthcare professionals, which can result in questions appearing to be rather alien to children. For example, it was only during Maisie's appointment that the consultant asked how Maisie and her Mum referred to her absence seizures. The consultant then re-asked how her 'moments' had been rather than her absences. Reframing the question to ensure a collective understanding can provide children with the opportunity to participate as fully as they wish.

Susanne explained why she chose to stay quiet and not be involved in her appointment:

Susanne: because I don't like to talk
Int: oh no, why not?
Susanne: I don't know, I think I'll just say something wrong
Int: what could you say that would be wrong?
Susanne: erm, I don't know I just, something silly!

Irrespective of her reasons to wish to remain quiet in the appointment, the hesitancy to say something in the appointment reveals how uncertain Susanne was regarding the value of her potential contributions. A similar notion was seen in Wayne's Mum, Robyn's quote above, illustrating his eagerness to provide a 'correct' answer (Curtis-Tyler, 2012). It could also be a demonstration of the unequal nature of the relationships between children, parents and healthcare professionals in the appointment and the dominance of adults being right discourse.

An aspect of the appointment that seemed to reduce children's desire to be involved was discussions on and around seizure activity. During Yasmin's appointment, for example, she responded well and appeared to be agentially engaged in the initial stages of the appointment about her wellbeing and how she was doing at school. However, when the consultant asked about recent seizure activity she looked to her Dad and then sat very quietly, her head dropped and eyes lowered, she avoided looking at everyone choosing instead to fixate on a mark on the floor occasionally kicking at it with her feet. This reaction to discussions of seizure activity was seen within 13 other children's appointments. Nicola described discussions about her absences as: "*annoying ... Just cause... I don't want to hear about them*". Children's hesitation in participating at this point of the appointment could perhaps also be due to the lack of knowledge or understanding about their seizures, as was illustrated in chapter 4. Many children (and indeed adults with epilepsy) do not understand or even know what happens during a seizure, so detailed questions around what they are about and what happens can be challenging for children to be involved in or even hear about (Schneider and Conrad, 1983; Moffat et al, 2009).

The moment the latest or recent seizures were mentioned and the children became quiet, questions from healthcare professionals were often then posed to parents. It appeared to be a break point in their interactions from which their participation did

not recover. Once the adults usurp the child's interactional role, the child's place and participation in the conversation does not seem to revert to its position. For example, despite Yasmin's initial contribution, the consultant and her Dad did not seek to encourage Yasmin's re-involvement or ask her further questions, and there was no attempt to re-engage her in the discussion. Without some intervention, there was minimal opportunity for the child to re-engage in the conversation or appointment more generally.

Similar silencing could be seen when a child did not feel heard (Spyrou, 2016). For example, Melanie initially responded confidently and accurately to questions about how she was doing and her medication. Melanie appeared comfortable with the discussion and asked (unprompted) about when she could stop taking her medication. The question was met by her Mum, Cathy, scoffing, and the consultant and ESN seeming surprised by the question. They then sought to explore where the question came from: it transpired that Melanie wanted to be able to go on sleepovers with her friends, the subtext being that the treatment regime restricted this. Cathy responded that she is able to do these things and the medication or treatment does not stop her. However, she does not offer an insight to why Melanie might feel that she is unable to participate in such activities. The consultant confirmed that a treatment regime need not stop Melanie taking part in things like sleepovers. The discussion then moved on to Melanie's school progress, and her initial question regarding stopping medication was left unanswered. The situation appeared unresolved for Melanie: in response to the change in subject, her head dropped and she visibly withdrew from the conversation, looking upset. This ended all of Melanie's involvement in the appointment, there were no attempts from either healthcare professional or her Mum to assist in re-engaging. This left Melanie appearing quiet and uninvolved, despite asking a personally salient question. Therefore, the conversational styles and habits between adults (parent(s) and healthcare practitioner(s)) can be seen to exclude and limit children's actual and potential (agentic) involvement.

This exclusion and the consequences of it can be particularly emphasised regarding Mike's, Iain's, and Yasmin's appointments and decisions that were made during their respective appointments. For example, Mike was initially included and engaged in the appointment by answering questions, but as the conversation turned to discuss a

genetic test and the requirement for blood to be taken, he became disengaged. This conversation was purely between his Mum, the consultant, and the ESN. There were no pauses to explain to Mike what was being discussed, or the reason why he would require blood to be taken. An appointment was quickly scheduled by the ESN for right after the current appointment. It was only when it was apparent it would happen very soon that Mike, who looked visibly distressed and had been asking what it meant to have blood taken, the ESN took a moment to explain to him the process of taking blood. At no point in the appointment did anyone ask if Mike would be ok to have his blood taken, there was also no attempt to involve him in the discussion or the decision. When I asked Mike how he felt about having the blood test, he replied, "*A wee bit awkward... Yeah, it was quite... I never knew it was going to be like that*"; illustrating, therefore, the lack of understanding and involvement he had in the decision and the process of having blood taken. Regarding the decision to take Mike's blood Wendy, his Mum, stated: "*He just takes it in his stride, anything you say to him he has to do he just does it, you know, so yeah*", suggesting an implicit compliance and acceptance of Mike's lack of visible autonomy in this, and similar, situations.

Likewise, in Iain's and Yasmin's appointment, neither were involved in the discussions between their parent and healthcare professionals on making changes to their treatment regime. The discussion on medication changes was between Derek (Iain's Dad) and the ESN, there was no attempt to involve Iain in the discussion or decision; Iain sat listening and was tracking the conversation by moving his head to look at whomever was talking. When I asked Iain about this discussion during the second interview, he shrugged and when I asked if he understood what had happened he said, "*Not very much to me but I'm sure it made sense to my Dad, but not very much to me*". Despite not personally understanding or being involved himself, Iain's statement indicates that the responsibility of his treatment regimes lies with his Dad.

Similarly, following Yasmin's appointment where the decision was made to increase her medications, I asked her about this decision; she remained silent, shrugging slightly in response. It was only when I asked her what she would say if she could go back and see the doctor again that she said: "*I would say I don't want to*". Yasmin has a different opinion to her Dad and the doctor yet did not voice it within the appointment; perhaps choosing this way to be agentic. There is also perhaps a lack of

understanding around the decision that has been made and what it means for her and her epilepsy.

The two decisions discussed above in Iain and Yasmin's appointment serve as an example of the discord between parents and healthcare professionals that was sometimes apparent during the consultation. During Iain's appointment, it was his Dad (Derek) who introduced the question of increasing Iain's medication dosage. He did not want '*to be caught on the back foot*', so mentioned the possibility of increasing Iain's the medication in conjunction with a recent growth spurt. Later, Derek spoke to me at great length about why he felt this was important:

We were caught out last time and we didn't know, nobody had told us that... although common sense should tell you that if somebody's getting bigger then obviously the medication that they're on won't be enough to keep them going, but nobody told us that so when he was having the worst spell we didn't know what was happening. And somebody had said to us 'look as he gets older...' just what she told us just now, keep an eye on him, if he gets a lot bigger, takes a stretch then we might have to see about his medication, but when that first happened we weren't told anything on that at all and it took its toll on us.

The negative impact of Iain growing and not increasing the medication is clear, and Derek has taken on responsibility for lessening this. During the appointment, Derek brought up these issues, though presented them as matters of fact rather than of concern: e.g. growth spurt and an increase in shakes implied medication should be increased. The ESN hosting the appointment did not agree and suggested that they wait to see if the shakes continue for a longer period. Derek did not look convinced, but nevertheless nodded agreement and the conversation moved on. Derek spoke about this decision not to increase medication in the second interview: "*No I'm quite happy, as I said to ESN I didn't think there was any need to increase just for the sake of it*". Hence, Derek offered a contradictory account both from what happened in the appointment and in regard to his own thoughts of wanting to keep Iain safe, seeming to accommodate the medical advice given.

Similarly, in Yasmin's appointment, the consultant initiated the discussion of increasing medication and asked Ash, Yasmin's Dad what his thoughts were on this; Yasmin was not involved in this. Ash, however, did not seem to want to answer the question, and avoided it by saying that he and his wife had considered it. He asked

the consultant what she would do, but the consultant continued to push him to provide an answer first before stating her opinion. The third time the consultant asked, Ash stated that he was uncomfortable with the idea of increasing her medication but was very quick to remind the consultant that it was their decision, not his. The consultant then suggested that they could wait and increase the medication in a month or two depending on how and if Yasmin's seizures continue, to which Ash responded by reiterating that if the consultant felt it important to increase the medication then that was ok with him also - although he looked very uncomfortable at this point. The consultant then suggested an increase in the medication, to which Ash agreed. In discussing this afterwards, he mentioned: "*the decision made, I don't know the medicine I am not sure*", when I asked how he felt about the decision, he responded: "*Yes it's okay but I don't know I mean I always go with the doctors, they know more about these things*". The observation and Ash's reflection on the decision demonstrates a holding back from openly acting against the perceived expertise and power dynamics within the appointment.

For parents, being able to talk openly, and honestly, was compounded by children always being present. Moreover, given that appointments were generally only held every four-six months presented issues for parents. There was never an opportunity to discuss the treatment, management, or the future without their children being present. Annie, Craig's Mum reflected her concern about speaking freely in the appointments:

Cause I think it can be quite scary for a child to hear, especially to hear a parent's fears and things as well. I remember one time I actually took a sheet of paper in and I had written things down and I just handed it over because I didn't want to verbalise it in front of Craig, so that's how I got around it.

The format of the appointment could lead to communication challenges in the appointment. For example, in Abby's appointment, the consultant noted that a genetic test had been carried out with Abby and her brother, and asked Abby's Mum, Shirley, if she had been given the results. She very quickly and sharply responded "yes". The consultant followed up and asked if Abby knew the results, to which her Mum responded sharply again with "no". The consultant then stated that he could explain what they meant to Abby if her Mum wanted. This explication continued for a few moments, with Shirley leaning off her seat and repeatedly saying "no". Shirley

became visibly more uncomfortable, and it was clear that she wished the consultant would stop speaking about the test. Shirley then implied that she did not feel Abby was ready. Abby seemed unaware of the tension and tracked the conversation with a confused look. The consultant seemingly noted her Mum's hostility, and changed the subject, to the clear relief of Shirley. Later in her interview, Shirley explained: "*I could have killed him. I mean I was screaming in my head 'shut up! Shut up!' He just wasn't getting it*". She did not wish to discuss the results with Abby at that stage, the genetic test had revealed a genetic predisposition to another medical condition, one that would potentially affect her life in the future but had nothing to do with epilepsy or her life at present. However, such concerns were not universal, for example, Wendy, Mike's Mum, described how "*if I've got any questions to ask or anything I do ask them, no point in sitting back, you know, if you're only there once every six months*". Thus, illustrating the flow and ease of communication differed amongst children and parents.

Rather than facilitating the enactment of, the clinical encounter has been shown to more often constrain and restrict. Children's tacit knowledge and lived experience of their condition can be seen to be variably received, with some suggestion of competence mitigating this, resulting in influencing children's opportunities to participate (LeFrancois, 2007; Deddings et al, 2014). Additionally, the unequal nature of the relationships between children, parents and healthcare professionals in the appointment and the dominance of the discourse of adults being right further serves to reinforce obstacles to involvement (L'Espérance and Orsin, 2016; Curtis-Tyler, 2012; Deddings et al, 2014). This is in contrast to the sense of ownership children reflected for their appointments. As Alderson (2007) and others (e.g. Shier, 2001; Hart, 1992), have previously stated, the degree to which children are able to participate in situations is dependent on how healthcare professionals and parents interact with them to elicit and engage their perspective.

5. After the Appointment

After the appointment had finished, it signalled the end of the visit to the hospital. All the children had very minimal reflections on the appointment afterwards; for example: "*It was good, not very exciting really*" (Abby), "*it was fine*" (Alex), and "*Bit boring... Don't know it was only talking*" (Nicola). Equally, only a handful of children reflected

on talking about their appointment afterwards with their parent(s); for instance, Iain reflected that *"whoever's taking me home I have a chat with them"*, and Phoebe said: *"yes, we talk in the car on the way home"*. This debriefing also offered the opportunity to clear up misunderstandings, as Colleen, David's Mum reflected: *"He said that in the car going home, he didn't understand a lot of what he was saying"*. For most children, though, the end of the appointment marked the end of the discussion of their epilepsy and treatment.

The end of the appointment also brought about a treat for eighteen children, with Craig noting *"I get my sweets after, then home"*. Also, John, Nicola's Dad recalled, *"we just came home, via McDonald's of course"*, referring to a conversation we had before the appointment about Nicola requesting a trip to McDonald's restaurant for tea because she had gone to the hospital. This idea of having a treat or a reward after the appointment was common and appeared to be part of the routine. As Cathy, Melanie's Mum indicated: *"we had a wee chat on the way home once I got her a magazine"*. This opportunity for a treat appeared to be an ingrained part of the rituals and routines of attending such appointments (Protudjer et al, 2009). The use of treats and 'perks' for visiting the hospital can offer parents a manner of compensation to their child and a means to manage the potential anxiety of visiting the hospital (Salmela et al, 2010). It can also reinforce a positive aspect of the visit to the hospital as Derek, Iain's Dad, stated: *"ahh we have to give him a wee treat after to put up with it all"*.

6. Summary

In summary, this chapter explored children and parents' experiences of attending and participating in a routine epilepsy clinic appointment. Attending the appointment has shown to form a routine and ritual for children and parents (Stewart, 2003; Silverman, 1987); yet, still causes nerves and uncertainty for most (Shier, 2001). The appointment itself can be seen as a complex web of negotiation and collaboration between the three participants: children, their parents and the healthcare professionals. The tone is set by the healthcare professional leading the appointment and the environment in which it is held. Children and parents are afforded very little influence regarding the tone and format of the appointment, further colouring their interaction and status (Tates and Meeusesen, 2001; Gabe et al, 2004). Despite this, most children reflected a

sense of shared ownership and the importance of the appointment for themselves (Tates and Meeusesen, 2001).

In terms of the involvement in appointments, it has been shown to be shared, varied and dynamic, as well as something that can, and is, rejected by children (Coyne, 2006a,b; Curtis-Tyler, 2015). Children's involvement in answering questions and talking was seen to have a variety of levels, depending on how they chose to agentially engage. Parents and healthcare professionals can impede and enable this involvement (and as a result children's agency) by failing to recognise or appreciate children's agentic potential or wish to be involved and by not taking time to explain aspects that could be misunderstandings (Gabe et al, 2004; Coyne, 2006b). Further, coalitions between parents and healthcare professionals often caused children to appear to be peripheral to discussions concerning them (Gabe et al, 2004). Children's own inputs from their experiential knowledge and understandings were not always considered as appropriate within the clinical discussion by healthcare professionals or parents (Prior, 2003; L'Espérancea and Orsin, 2016). This was clearly seen through healthcare professionals repeating questions asked of children to their parents. (Young et al, 2002; Kime et al, 2013). Although, multiple sources of information can provide clinical value the perception of repeating questions and conversations must be carefully considered by healthcare professionals for the implications it has for how children feel involved and heard (Sanz, 2003; Fox et al, 2005). Parents own interactions with healthcare practitioners can also illustrate the dominance of the medical profession and associated expertise, minimising parents' agentic potential in this context (Prior, 2003).

Thus, clinical appointments can serve to constrain, or thin, children's agentic potential, through its context and setting, the inter-generational and power differentials present and the lack of recognition of children's own experiential knowledge and understanding. Facilitating, or strengthening, children's agency in appointments requires parents and healthcare professionals to be attentive, sensitive and supportive of each (individual) child's expressions, experiences and perceptions (Klocker, 2006; Soderback et al, 2011). As a site of care, children's agency has been shown to be overlooked, with parents and healthcare professional's need to discuss treatment and management being prioritised.

Chapter Eight: Discussion and Conclusion

1. Introduction

The research presented in this thesis sought to explore children's experiences of living with childhood epilepsy and their involvement in the treatment and management of their condition in the home and clinical settings. How parents supported and shaped children's understandings and involvement in their treatment and management across these settings was also examined. Two separate interviews with children and their parents and an observation of a routine clinical appointment provided the means to examine these aims and the three underpinning research questions:

1. What does having epilepsy mean to children?
2. To what extent do children perceive themselves as actively involved in the management and treatment of their epilepsy within informal care practices in the home and formal health care settings?
3. What are the support and information needs of children with epilepsy?

The qualitative approach to these research questions allowed children's own perspective to be directly obtained. Previous research has neglected this stance in favour of parental accounts (Harden et al, 2016) or focused on specific, negative aspects of having epilepsy (Scambler, 2004; Barlow and Ellard, 2006). The findings from this research has demonstrated the value of obtaining children's own views and experiences, alongside their parents, by providing a rich appreciation of how their viewpoints diverge, intersect, and influence one and another.

Additionally, the findings have shown how children's agentic involvement in their care is shaped by parents and healthcare professionals through the provision of knowledge and perceptions of vulnerability. Children's opportunities to enact agency and their involvement was consequentially variable and context dependent. Parents implicitly and explicitly constrain children's agency and opportunities for enactment. This has informed our understanding of what care and agency, as two separate, but interconnected concepts mean in the context of childhood epilepsy. Thus, the research produced represents an original piece of work, through addressing gaps in

the sociology of childhood and clinical literature on childhood epilepsy, care and agency.

This chapter will bring together the elements of the thesis to explore the research questions in more detail. I will first present a summary of the findings addressing each of the research questions, before exploring them in the context of sociology of childhood health and illness. Specifically, discussions of care and agency will be drawn on to assist in developing a deeper understanding of children's experiences and involvement in childhood epilepsy care. Concluding thoughts will then be made, including reflections on the strengths and limitations of the study and associated implications for healthcare professionals. A final conclusion will then be presented.

2. Summary of Findings

This section will summarise the key findings in relation to the three research questions first posed, and detailed above. How these findings connect to theoretical discussions of care and agency will be explored in the third section.

2.1 Research Question One – Meanings of Epilepsy

Drawing on the first research question, the meanings children develop of epilepsy were most frequently developed through their own tangible experiences of the condition and from what their parents had told them about it. Concerning their understandings of treatment, all children emphasised the importance the medication had in preventing their seizures. Their further conceptualisations were again predicated by how others (overwhelmingly, parents) discussed treatment with them, resulting in many being unfamiliar with the more clinically accurate terminology linked to their medications. Seizures were often also understood through the bodily sensations experienced and occasionally by what parents had told or shown them (through videos). Thus, the identifying features of their medication and the tangibility of their treatment regimens and seizures were how children conceptualised their epilepsy and gave it meaning.

Parents, as the primary gatekeepers of epilepsy knowledge (according to children and parents), detailed their control of how and what they wanted their child to understand

of their condition. Ultimately, parents were influential in how epilepsy became incorporated into their child's life. Protection and competency were cited as reasons by parents as to why and how they managed the information available to their children. The meanings of epilepsy crafted by children were influential in their experience of treatment and management regimes.

2.2. Research Question Two – Children's Involvement in Treatment and Management of Epilepsy

The majority of children reported a shared responsibility alongside their parents for their epilepsy care. Mostly children spoke of self-assigned responsibilities for themselves, including: remembering and taking their medication, looking after themselves after seizures occurred, and more generally, and participating in clinic appointments. Beyond their self-assigned responsibilities, there were a range of differing views on involvement from children, with some wanting more (e.g. recognising their own emerging autonomy) and others less (e.g. viewing care as their parent's responsibility, choosing not to engage). Parents, however, did not always recognise children's self-assigned responsibilities or roles in care. The administering of medication and mitigating risk of harm from seizures was seen for many parents as their ultimate responsibility, often overshadowing any role children had within it. Children and parents reflected how the taking of medication had become embedded in their everyday routines, with both discussing strategies they had independently developed to ensure the medication was taken appropriately (e.g. creating a 'cocktail' or by not taking a drink afterwards).

In clinic appointments, children viewed parents' contributions and presence as vital, often as the key contributors to the discussions with healthcare professionals. This was also reflected by parents themselves. Children's own involvement in the appointment was variable and dependent on the types of conversations being had and the facilitation skills of parents and healthcare professionals. Yet, as I observed in the clinic appointments, their involvement was not necessarily recognised and did not always appear to be particularly appreciated, serving to limit and constrain children's attempts to be involved during appointments. The accounts of the children and parents largely confirmed this interpretation. The study has also highlighted differences and similarities between the two 'caring' contexts – the home and the

clinic – in children’s and parents’ experiences and perceptions of involvement. These differences and similarities will be drawn out further in discussing the conceptualisation of care and implications for understanding agency in the next section.

2.3. Research Question Three – Support and information needs of children

The third, and final, research question was less obviously identifiable within the data. Only a handful of children identified or spoke of their requests for further information regarding epilepsy and even less spoke of support needs directly. In terms of information, a small number of children spoke of wanting more information regarding their condition, with a few children asking questions during the interview about it and about other children with epilepsy. As with children, many parents were content with their level of understanding and access to epilepsy information. A number of parents did reflect on feeling uncertainty and uneasy about how much information they should be providing children about the realities and potential future of their epilepsy. With discussions of children’s competence, vulnerability and age being factors determining this for parents.

In terms of support, although no support needs were spoken about directly by children in regard to taking medication, it was clear that many had developed their own strategies to aid them. This revealed a potential need for further support from parents and healthcare professionals. Also, the research identified potential support needs for children in relation to negotiating their involvement in treatment and management regimes at home and during discussions in their clinic appointments. Additionally, many children reflected (implicitly or explicitly) on feelings of difference due to their epilepsy. Parents and children indicated a lack of epilepsy support systems, aside from healthcare professionals, with many relying on immediate family for support instead, illustrating further potential support needs.

In sum, the research has produced relevant and interesting findings that directly address the research questions. The next section will explore these findings further through the lenses of care and agency. In particular, what care means in the context of childhood epilepsy and for children, the implications care has for children’s agentic opportunities, and the influence of parents and healthcare professionals on both

children's conceptualisation and involvement in their care and the concept of agency will be explored.

3. Meanings and Involvement: Care and Agency

This section will explore how the meanings of epilepsy and care interconnect and influence children's agentic involvement by drawing on the findings from this research, relevant empirical literature and theoretical discussions (first set out in the literature review). I will first explore how children and parents conceptualise care associated with their epilepsy before then moving to examine how such conceptualisations can contour the enactment of children's agency and subsequent involvement in their care. In doing so, I will draw on Klocker's (2007) notion of 'thinning' and 'thickening' of agency, to convey the complexity and variability of children's agency in different circumstances. I will then summarise, highlighting agency and care as separate but interconnected concepts and the additional insights that are provided to both concepts when considering a child's perspective.

3.1 Conceptualising Care

Care has been conceptualised by many, across diverse theoretical positions, covering aspects of love and labour, obligation and responsibility (see chapter 2; Brannen and Heptinstall, 2003; Philips, 2007; McLaughlin, 2012). How care has been provided and received has equally been contested and refined (Noddings, 2003; Kroger, 2009). However, children's perceptions and understandings of care have been only nominally examined (Brannen and Moss, 2003; Percy-Smith and Thomas, 2010).

I have shown that children intrinsically link their understanding of care through their experiential knowledge of epilepsy. What 'care' meant to the children was grounded in the practical, tangible experiences of their epilepsy treatment regimes and management strategies. Specifically, care was conceptualised through 'activities of care': medication remembering, administering, and taking, the managing of seizures when they occur (practically and through support and reassurance), restrictions to their activities to keep them safe and attending clinic appointments. These features were considered by children as activities of care (i.e. a means to keep them safe and 'free' from seizures), as well as providing them a way to understand their epilepsy.

For parents, care was conceptualised through their enactment of perceived parental responsibilities and the normative constructions of children (as in need of parental care); parents were a protector, protecting children from harm (physically and emotionally), and an advocate for them (at home, school, and in clinic appointments). The protective dimension to care was clearly demonstrated through the many strategies' parents adopted to mitigate potential harm in case seizures occurred. These often included controlling children's activity and independence to address risk and potential vulnerabilities. This resulted in children being the subject of surveillance and monitoring by parents or others around them (McNamee, 2013). The risks and vulnerabilities reflected parent's fears of 'what could happen' if seizures occurred. This fear was compounded by the uncertainty of seizures and made the times of treatment change (i.e. points at which seizures could become more frequent) hot spots for parents' insecurity. The fear and uncertainty of potential harm and how others may react to the condition (through stigmatisation or displaying negative reactions) was also a prompt for parents' protective impulses (Green, 2003; MacDonald and Gibson, 2010).

The vigilance and monitoring of children that encapsulated this form of protective care, was frequently discussed as a 'balancing act' alongside ensuring children had a 'normal' childhood. Parents reported concerns of 'getting the balance right' and whether they were 'being too harsh or restrictive' on their children due to their diagnosis (Churchill, 2011; Pitchforth et al, 2011). Attaining such a balance also engendered a negative dimension of care, either parents allow their child to be placed in potential danger or instead risk over-protecting them (Brannen et al, 2000). This was mitigated only by time, when the severity of the condition was felt to be reducing and by the recommendation of healthcare professionals.

Children also discussed similar protective components of care; the majority reflected that their parents' key caring role was to protect them. The protective element to parents' care was also seen by children as a justification for parents' decisions and actions to restrict their activities to ensure they were not harmed by seizures (Brannen and Heptinstall, 2003). The monitoring and surveillance experienced was presented by children as being for their own wellbeing and safety, not as an inconvenience (for most); though a few parents did allude to their child's initial resistance to associated restrictions. Children's acceptance of parents' role as 'protector' highlights the

significance of discourses around parental responsibility in shaping both children's and parents' views of care in the context of epilepsy (McLaughlin, 2006; Such and Walker, 2004; Churchill, 2011; Wyness, 2015).

Despite primarily conceptualising care slightly differently (as a practical activity by children and or as a means to protect by parents), children and parents both reflected a shared dimension to their reflections on care. The shared endeavour of care was predominantly seen through their discussions of treatment regimes and the process of taking medication in the home. Although children were the only ones to actually take medication and subject to treatment regimes, parents experienced the process with them (Meah et al, 2010). The blurring of such distinction emphasises the perceived importance of treatment care practices to children (to stop their seizures) and parents (connecting to their need to protect). As well as indicating how children conceptualised their involvement in such care practices. The recognised mutual benefit of treatment regimes adds a dimension of mutuality to children and parents' conceptualisations (Tronto, 1993; Brannen et al, 2000). The shared dimension of care will be further examined as I explore children's agentic involvement in care in the next section (3.2).

A further dimension of children's and parents' conceptualisation of care developed from the everyday nature in which the care, and their epilepsy, was experienced. Both children and parents spoke of care and its practices with a sense of ordinariness, reflecting how the treatment regimes had become embedded in their everyday life (Prout et al, 1999; Morse et al, 2000; Protudjer et al, 2009). The taking of medication had become embedded as part of their wider routines of family, taken with breakfast and dinner, or coordinated with bedtimes. Similarly, when seizures did occur, a further sense of ordinariness associated with seizure activity arose. Children and parents' spoke of patterns of caring activity that would happen immediately after a seizure occurred, e.g. being placed in a safe position, attending the hospital. Although not necessarily part of their daily care practices, a sense of routine to seizure management also developed. The routinisation of treatment and management emphasises an entrenched nature of care and care practices in family life, and how children and parents had together formed these practices of epilepsy treatment and management further indicating an interdependent element to care (Prout et al, 1999; Morgan, 2011; Pitchforth et al, 2011). These embedded care practices can be seen in contrast to other

childhood chronic illnesses, where daily life can become structured around care and treatment regimes rather than embed alongside family life (Rehm and Bradley, 2005).

Building on these notions of ordinariness, the very nature of the care experienced further facilitated and enabled children to have a 'normal life'. The almost invisible nature of treatment regimes, hidden in the home, and the treatments ability to 'stop' seizures, meant that for most children there were no 'outwards' signs or symptoms of them being different or not 'normal' (Guell, 2007). With treatment regimes enabling a 'normal' life, children and parents could project an image of a normal childhood and hence being 'non-different' to others. Most children were still able to be involved in activities similar to their peers including attending school, appearing normal – their epilepsy, and its associated care practices, hidden from view. Thus, care enabled children to 'fit in' with their peers and avoid being seen as different, maintaining a broader sense of a 'normalised childhood' (Protudjer et al, 2009).

The constructing of care as a means to appear 'normal' (and maintain ordinariness) is reinforced through the many negative aspects most children described of their condition; what it meant for them to have epilepsy and what it meant for others to know/or to be seen to be epileptic or different. This replicates previous findings around the felt stigmatisation of epilepsy and feeling different (e.g. Harden et al 2016; Benson et al, 2017; O'Toole et al, 2017). As Bernays and colleagues (2015) found, instead of HIV treatment providing children a sense of wellbeing and normalcy, it served as a means for children to deny their HIV status. Children thus conceptualised care as providing them the means to hide, perhaps even deny their diagnosis and the presence of their epilepsy; this was reinforced by children's limited voluntary disclosures of their epilepsy.

The promotion of normalising epilepsy and its care practices and activities was heavily endorsed by healthcare professionals. The emphasising of a 'normal childhood' is advocated as a desirable clinical strategy in the context of chronic conditions and illnesses (e.g. Rehm and Bradley, 2005). Such an approach could, however, lead children to perceive their condition as deservedly stigmatised, shameful, and something that should not be spoken about (Benson et al, 2017; Jacoby and Austin, 2007; Ryu et al, 2015), placing parents in a double-bind. Consequently, concealing or

normalising their epilepsy care could inadvertently reinforce children's feelings of being different, as was reflected strongly across the four data chapters.

However, the need for care cannot be denied, rather it became the reason, for some, as to why their diagnosis of epilepsy was revealed. Parents reported having to tell teachers or their child's friend's parents about the diagnosis to ensure that appropriate care was put in place for their child in event of a seizure. Medication taking also revealed the diagnosis when it was required to be taken out of the home, on school trips for example. Therefore, the care practices that provided the sense of normality also identified children as different, creating an uneasy contradiction in how children understood and conceptualised care (Protudjer et al, 2009; Benson et al, 2017).

In sum, for children and parents care can be conceptualised through the practical components of treatment regimes and management strategies; the development of routines and rituals that are crafted and endorsed by both (Dermott and Seymour, 2011). Building on this, care can be considered a form of ethical activity and moral thinking in which both children and parents engage – encompassing perceptions of stigmatisation, feelings of difference and sameness. With this, children's perspectives of care cannot be captured by the dichotomous approach which has been previously applied to care, as either labour or love (Brannen and Heptinstall, 2003). Rather children's conceptualisations of care weave together the practical, emotional and collective practices through which children and their parents together create and recreate daily family life (Lutterell, 2013). However, with parents (implicit and explicit) need to protect and the emphasis being placed on 'normality', children can appear passive to the care parents provide (Kleinman, 2012; Brannen and Moss, 2003). In doing so, children and parents echoed normative constructions of parenthood and childhood, the moral duty parents have to provide care, and discourses of caring for children (Kleinman, 2012; Perala-Littunen and Book, 2012). However, the findings from this research has illustrated the need to look beyond how children conceptualise care to explore how they are involved (agentially or otherwise) in care. The next section will explore children's agentic involvement in their epilepsy care and how care itself can serve to encourage and constrain their agentic potential.

3.2 Agentic Involvement in Care?

How care is (independently and dependently) conceptualised by children and parents can shape the enactment of children's agency, and subsequently how children's involvement in care is perceived. This section will explore how children and parents' conceptualisations of care and the different contexts of home and the clinic can foster and inhibit children's agentic opportunities and capacities in their involvement in care. The discussions of agency from the literature review will be drawn on to examine the complexity and variability of children's agency in different circumstances.

As illustrated in the previous section, children conceptualised their care through the practical and tangential components of epilepsy treatment and management. In discussing these aspects of care children also reflected on their own involvement (see chapter 6), and connectedly, their agentic contributions, to care. Most children described a responsibility to remember and take their medication, appreciating the importance of their treatment regimes. Children's active and self-defined role in their self-protection through presenting, maintaining, and protecting their normality was also illustrated. Some, explicitly sought to hide their seizures from others; for example, by pretending something else was happening (e.g. by pretending to look at something instead). These attempts minimised disruptions to, and protected, their presentations of normality (Green, 2003; Lewis and Parsons, 2008; MacDonald and Gibson, 2010) and illustrated children's agentic attempts to protect their sense of self, internalising aspects of stigmatisation through their own initiated agentic behaviour (Lewis and Parsons, 2008; Meah et al, 2010). These contributions to care illustrate children's perceived opportunities and enactments of agency, demonstrating that agency can be circumstantial and directed, not always all encompassing and universal (Valentine, 2011).

Yet, these agentic actions regarding their treatment and management took place without disturbing or challenging the social order of the family routines and care practices – many without being necessarily recognised by parents (Moran-Ellis, 2013; Brannen and Moss, 2003). Only a few children raised minor issues or questioned their care practices during the interview; there was minimal indication that any such concerns were raised with parents. This partially supports Harden and colleagues (2010) study of working parenthood, where they queried children's abilities to question their routines, motives and attendance in everyday activities, and obtained data that suggested children did not wish to 'rock the boat' with parents.

Connected to this, children in the study provided brief and limited responses regarding their involvement in the negotiation of the care practices and routines, suggesting that children's roles in care were minimally negotiated. Parents were frequently seen as managing any negotiation of care and limiting their children's opportunities for involvement at home due to their perceptions of their child's competence (e.g. not managing their medication alone). Some children did reflect on the negotiation around the differing levels of risk acceptance between them and their parents in their care at home (Henwood et al, 2008; Olsson, 2017). Some presented their parents' care or the restrictions placed on them by their parents (due to their epilepsy) as constraining, with some pushing back against their parents as an illustration of their felt potential agency (Brannen and Moss, 2003; Stjerna, 2015). However, not all children negotiated or sought more involvement or agentic opportunities at home (or in the clinic). This reflects the dependence some children noted on their parents to manage their epilepsy care at home (and in the clinic), indicating their limited appeal in negotiating of care or caring responsibilities. Through not 'rocking the boat' or actively negotiating involvement children can inadvertently reflect a passivity towards their care (being simply a receiver) and lacking of agentic capability/competency.

As Meah and colleagues (2010) advocated, however, such actions and behaviours are more complex than children simply complying with adult instruction and prescription on their care. Rather, children are illustrating their agentic contribution to their care through their continued maintenance, participation and support of the routines and care practices they reflected developing alongside their parents. To this end, children have mobilised their agentic resources in subtle and discreet ways (Moran-Ellis, 2013; Brady et al, 2015), implicitly engaging in their care (Brannen and Moss, 2003). Similarly, acts of resistance by children (e.g. choosing not to take medication) are viewed as disruptive or disobedience of adult instruction yet are still reflective of an agentic actor (Christensen, 1998).

Yet, many parents and healthcare professionals did not necessarily recognise children's 'positive' agentic contributions to their care; instead, noting the 'negative' actions of resistance (Wyness, 2013; Brannen et al, 2000). This was particularly apparent around taking medication and the management of seizures, for example, the strategies children adopted to make medication taking more palatable was not

(explicitly) noted by any parents. By overlooking their agentic involvement and the roles they have in their care, parents (and healthcare professionals) perpetuate inter-generational power imbalances and emphasise a conceptualisation of agency that is direct and purposeful, implicitly 'thinning' children's agentic opportunities and potential (Meah et al, 2010; Zeiher, 2001; Brannen and Moss, 2003; Valentine, 2011).

Although not necessarily recognising their child's agentic contribution at home, many parents and healthcare professionals sought to explicitly encourage their involvement in epilepsy clinic appointments. This active encouragement was rarely seen in the home and most frequently associated with attending clinic appointments, demonstrating a disjunction between recognising agentic potential and involvement in the two caring contexts. Many parents attempted to foster children's agentic potential and provide them the opportunity to be actively involved through discussing appointments in advance, encouraging their child to engage in questions. Yet, as illustrated in the fourth data chapter, this preparatory engagement effort did not always lead to parents and healthcare professionals appreciating children's agentic involvement nor was it sufficient to ensure children were afforded agentic opportunities in their appointments.

Despite best intentions of parents to encourage agentic involvement in their care, many also (explicitly or implicitly) disrupted or limited their child's agentic potential as well (Tisdall and Punch, 2012). As noted in the previous section, parents' primarily conceptualised care through their moral obligation of protection; protecting children from harm and keeping them safe. Through this, many parents spoke of their wish to protect children from the realities of the condition, and consequently chose to withhold certain information about epilepsy. This was most notable regarding parents' use of metaphors to describe seizure activity rather than more (descriptive) medicalised language and their refusal to tell children of SUDEP (Sudden Unexpected Death in Epilepsy) (Dawood et al, 2015; Webster, 2017). Parents decided that it would be in children's best interests to withhold these aspects of information and not provide a clinically detailed explanation of epilepsy, protecting them (Benson et al, 2017). This strengthens Benson and colleagues' (2017) findings on parent's perspectives of disclosing epilepsy to their children; they found that the greatest challenge for parental disclosure was parents' view of themselves as 'protector' of their child. The role manifested as a responsibility for "sheltering their child from harm

and maintaining their child's sense of normality" (Benson et al, 2017: pp.43; see also: Alderson, 1993; Bluebond-Langer and Korbin, 2007). The reduced discussions of epilepsy between children and parents, resulted in the (almost) silencing of it by parents, thereby reinforcing children's normality and projection of a 'normal childhood' to children by parents. This could itself also inform a stigmatised conceptualisation of epilepsy for children, suggesting that epilepsy may be perceived as something that should not be spoken of as well as hidden from others (O'Toole et al, 2016; Schneider and Conrad, 1980), as I illustrated in the section above when examining the normalising of epilepsy care.

Parents' discursive filtering of epilepsy, also assisted in structuring of their child's understanding of their condition and its associated treatment and management. For example, very few children fully understood what epilepsy was or meant beyond their seizures or medication. Due to this, children did not necessarily have the opportunity to develop a fuller grasp of the nuances, and realities of epilepsy and its associated care (e.g. SUDEP, future prognosis). The selective filtering can be seen to protect children from the reality of the condition, but it also serves to reinforce their perceived vulnerability and lack of competence in digesting such information.

Connectedly, in considering the clinical setting, the selective structuring of children's understanding of epilepsy reduced their ability to communicate about their condition and its care in ways that would be considered appropriate (Ironsides et al, 2003; Thompson et al, 2012). Children are expected to communicate using appropriate clinical terminology and frames of reference that may not be familiar to them or make use of experiential expertise they had developed (Coyne, 2006a; Brannen and Moss, 2003; Thompson et al, 2012). This is further compounded as parents and healthcare professionals placed limited value on children's own lived experiences and the knowledge they create from it (i.e. their experiential expertise; Thorne et al, 2001). For example, children's descriptions of seizures through metaphors or bodily sensations or of medication through its colour or dosage, could be easily disregarded as poorly-informed. Using such language, rather than the clinically appropriate terminology or means of discussing epilepsy, meant that children did not follow the discursive rules of the quasi-scripted communication that is frequently required in clinical settings (Coyne, 2006a; LeFrancois, 2007). There is an assumption that children need to have certain kinds of linguistic cognitive skills before they can be considered social actors

or their actions to be understood as agentic and to demonstrate competency (Moran-Ellis, 2013).

Consequently, limiting children's understanding of their condition dis-empowers and diminishes the resources they have available to further mobilise their own competencies (Oswell, 2013; Moran-Ellis, 2013). The discursive rules of the clinic and parents' filtering of epilepsy knowledge and understanding can 'thin' or constrain children's agentic potential and shape the opportunities they have to be agentic. Moreover, it emphasises the lack of recognition of children's own understandings (Thorne et al, 2001) and places limited value on their own wealth of 'insider' experiences and knowledge (Prior, 2003; Coyne, 2006b; L'Espérancea and Orsin, 2016). As Christensen (1998) argued, competence is not a psychological property of an individual, but a relation between individuals in the context of negotiation and interaction. The question is not what children are or not able to do, but how their competence about their condition is articulated and in the context of what kind of social interactions (Christensen, 1998). Thus, it is through children, parents and healthcare professionals' interactions that perceived competence, of each other, is crafted. As a result, the perceived competence parents' and healthcare professionals' project on to children, or that is felt to be projected by children, influences children's ability (and perceived ability) to demonstrate agentic involvement in their care (Christensen, 1998; Balen et al, 2006).

The different experiences of epilepsy as a condition and associated knowledge and expertise children and parents develop can reflect and reproduce (implicitly or explicitly) existing forms of (generational) power differentials (Mayall, 1998; Närvänen and Nasman, 2004; Conrad and Barker, 2010). The inter-generational power structures within which care is conceptualised, enacted and developed, are influential in determining and shaping children's agentic potential and opportunity (Mayall, 2002; Bluebond-Langer and Korbin, 2007; Singh, 2013). Power can be both exercised and resisted in child-parent relationships (Punch, 2005), and with healthcare professional. As Valentine described: "parents' superior age, size and life experiences means that their power over their children is literally embodied" (pp.150, 1999), illustrating the predefined and normative constructions of parents (and similarly healthcare professionals) which provides them power by default (Punch, 2005; Mayall, 2015). The clinic environment can further reinforce, and emphasise power relations between

children, parents and healthcare professionals (Gabe et al, 2004; Tates and Meeusesen, 2001). In the clinic observations, children and parents had to wait for healthcare professionals to be ready to see them with frequent delays, and when they did enter the appointment, it was often set up in a way that promoted the healthcare professional as in charge of the discussion, and consequently, in control. Similar arguments have been made regarding the school environment, as Devine (2002) stated, school can be viewed as symbolic of the power relations between adults and children in school and reflects children's lack of ownership, power and control within the school environment. The balance of power is consequentially not evenly distributed between children, parents and healthcare professionals in the home or clinical context (Kirk, 2001; Callery and Smith, 2005).

In the context of the clinic appointment, children demonstrated many attempts to enact agency (and seeking opportunity to display agency as well), including for one child raising his hand. The observations of appointments also revealed potential acts of agentic resistance through little actions children made, such as glancing at phones or other aspects of the room (not people), or being the first one to get up and leave the room at the end of the appointment, for example (Mayall, 1998; Devine, 2002; Klocker, 2007; McNamee, 2013). Yet, there was often limited recognition of their agentic contributions (or hindrance) in the clinic or ability to negotiate within the caring process - children's age and presumed/perceived competence compounding perceptions of their agentic potential (Silverman, 1987; Christensen, 1998). Instead, parents and healthcare professionals' formed 'coalitions' overshadowing children's agentic attempts or opportunities (Gabe et al, 2004). This was reinforced through healthcare professionals' repetition of clinical questions and the dominance of conversation between themselves and parents to the detriment of children's involvement or inclusion (Coynes, 2007; Curtis-Tyler, 2015). This served to thin children's agentic potential and further reinforced how healthcare professionals do not necessarily acknowledge the legitimacy of children's experiential expertise, associated understanding and means of communication (Brannen and Moss, 2003; Curtis-Tyler, 2015).

Similarly, children's agentic attempts to hide their condition can be inadvertently disrupted (or thinned) by parents and other adults when their epilepsy diagnosis is disclosed on the basis of care and safety needs. Parental protection and their desire

to ensure children stay safe has further 'thinned' children's agentic potential. This highlights a contradiction in different agentic needs and agendas, as well as the (generational) power adults have over children (Brannen and Heptinstall, 2003; Wyness, 2015). As a result, this places children in a position of perceived vulnerability and dependence influencing their care experience and involvement, and how care is more broadly conceptualised (Murray and Barnes, 2010). Parents, and healthcare professionals, are in the position of power to choose whether or not to negotiate roles and care-giving, while children can be viewed as in a weaker position to change routines or roles in the caring-relationship (Kirk, 2001; McLaughlin, 2006).

As a result, despite successive legislative and policies (e.g. Scottish Executive (2007) and RCPCH (2014)) seeking to ensure children's 'voices' are heard and viewed as autonomous actors in relation to their own healthcare has not been robustly demonstrated (Hill and Tisdall, 1997; Kelly et al, 2012). Rather, children's involvement can be broadly considered as tokenistic – present to an extent but not necessarily meaningful to their care, associated decisions, or fully respected (Hart, 1992; Sinclair, 2004; Tisdall, 2017). Parents withholding (implicitly or explicitly) information and conversations on epilepsy and their overriding moral imperative to protect has limited the resources children can draw on and reduced their opportunities to fully engage with their epilepsy care. This serves to thin children's agentic contributions and opportunities in the clinic and in the home, restricting children's participation and resulting in a poor quality, tokenistic, involvement (Sinclair, 2004; Tisdall, 2017). It is thus necessary to move beyond tokenistic participation or suppressing of children's agentic involvement, to consider how children's experiential expertise and experiences can be valued through their active involvement as different, but yet active equal agents of their care and consequentially as integral to the caring relationship (Sinclair, 2004; James, 2007).

3.3 Summary: Reconceptualising Care and Agency

The study and subsequent discussions have demonstrated how children and parents experience and conceptualise epilepsy both similarly and differently (Mayall, 1998; Rudestam et al, 2004). The differences between their perspectives have illustrated the nuances and paradoxes of how care and agency are conceptualised and enacted in the context of childhood epilepsy. Parents overarching conceptualising of care as

protection and as their moral responsibility, reflected through the inter-generational power dynamics, can eclipse, and ultimately thin, children's agency. Such conceptualisations by parents promote children as passive recipients to their care and subsequently, intentionally or un-intentionally, limit children's potential agency and opportunity for involvement (Brannen and Moss, 2003; Pradel et al, 2001). Accordingly, parent's conceptualisation of care resonate with those articulated by feminist writers, who have emphasised the emotional exertion and familial duty of care (Kleinman, 2012). Furthermore, it recognises disability writers' notions of care as disempowering for the care-receiver, children, and enhances their perceived vulnerability, passivity, and lack of autonomy (Watson et al, 2004).

Children also respected the need for protection as a fundamental part of their care, but rather conceptualised it alongside their own agentic involvement in keeping themselves safe and seizure-free – moving an understanding of care away from the formulations of feminist writers (Williams, 2001). Through utilising their experiential expertise and available material resources children agentially engaged, to varying degrees, in their care at home and in the clinic. Children's (active and passive) contributions to their care were however recognised and appreciated to differing extents and dependent on the situational context (Hutchby and Moran-Ellis, 1998).

Children and parents partly conceptualised care as a shared or joint endeavour illuminating a sense of mutuality to care practices (Pradel et al, 2001). Children's agentic contributions through enactment of agency to maintain the shared routines of treatment and management practices was documented. Yet, despite recognising their child's involvement in the care practices, parents did not necessarily appreciate children's agentic contributions (Brannen and Heptinstall, 2003). From parents' positions, there was minimal co-operation or sharing of care, instead children were seen as dependent and passive to their defined routines and practices of care. Children's contributions remained subordinate to their parents' and healthcare professionals' positions, rendering their agentic involvement in their care practices often invisible (Christensen, 1998). The contradictory perspectives highlights how care should be understood as consisting of several dimensions beyond the care-giving and care-receiving model of care (Tronto, 1993). The mutuality of care experience from children's perspectives echoes Tronto's ethic of care (1993) with the dynamic nature of care and caring relationships being emphasised over the individual (child/parent)

and their connected autonomy (1993; Rummery and Fine, 2012). Thus, in conceptualising care with an interdependent dimension allows us to understand the autonomous elements of care (Tronto, 1993).

Consequently, the study has demonstrated how agency, in the context of childhood epilepsy care, is a “complex, multidimensional and ambivalent” concept (Valentine, 2011, pp.348), with issues of recognition and misrecognition both significant (Wyness, 2015). Care provides a variety of contexts and activities of action across a continuum of varying interactions and conceptualisations that can serve to 'thin' and 'thicken' children's agency - implicitly and explicitly. Care can serve as the reason to 'thin' agency (through the need to protect), yet it can also provide a reason to encourage 'thickening' (through recognising the importance and participation within). These nuances of agency, alongside power imbalances, must be considered when exploring care in the context of children as opposed to adults. Since expecting children to be able to communicate and participate in their care (at home and in the clinic) in the exact same way as adults is neither realistic nor desirable (Brannen and Moss, 2003). Rather, there needs to be a responsiveness to care that considers children's experiential expertise, agentic contributions, and as stated, the inter-generational power imbalances, that are shaped by and with children and parents/healthcare professionals (Tronto, 1993; Brannen and Heptinstall, 2003). Similarly, there needs to be a recognition of agency as a situated accomplishment that can vary in scope and scale, which forms part of the complex set of processes and practices that shape children's experiences of care (Moran-Ellis, 2013; Brannen et al, 2000).

4. Final Reflections and Insights

This final section of the thesis will reflect on the study and research as a whole including addressing the strengths and limitations and future research directions. Take-home insights for healthcare professionals will then be suggested, offering a practical application of the findings. A final conclusion will then be drawn.

4.1 Strengths and Limitations

One of the strengths of this research study was the direct focus on attaining children's own perspectives, understandings and experiences of their epilepsy and their involvement in its associated treatment and management. Furthermore, the

qualitative methods used and their application in exploring these experiences have provided nuanced insights, reinforcing previous findings from existing studies whilst also serving to enhance our understanding of children's involvement in their home and clinically-based care. The findings have demonstrated how epilepsy and care experiences are shaped by complex, multi-faceted considerations both inside and outside of the home and clinic. This is the case specifically regarding the experiential, normalised, negotiated aspects of care and the caring responsibilities and power dynamics at play. The findings have also contributed to sociological literatures on childhood, health (with regards to epilepsy experience) and care.

When considering the limitations of this research, there are a few points for reflection. My role as a researcher, the purposes of my research and connectedly the reason for my presence in certain children's clinic appointments was not a secret to the children, parents', or healthcare professionals involved. This understanding of my research and my presence in clinic appointments could have altered how children and parents participated, as well as how they and healthcare professionals engaged with their clinic appointment. Although reassurances were made that my research would not pass judgement or be critical of practice or thoughts, it could have been taken in such a way.

By virtue of the focus of the research and the methodological approach applied to exploring the research questions, the study can only speak of the experiences of a small number of children and parents who chose to be involved in the study. This has, of course, limited the generalisability of findings. More specifically in regards to the sample, the participants were subject to inclusion and exclusion criteria that meant the final sample had relatively uncomplicated epilepsy. In other words, the children involved in the study had relatively few, if any, co-morbid conditions (or developmental delays) alongside their epilepsy diagnosis and comparatively had well controlled epilepsy (Appleton and Marsh, 2009). The findings in this study cannot therefore be considered to be representative of all diagnoses of childhood epilepsy where there are co-morbid conditions.

Similarly, all participating children had been diagnosed at least one year prior to the interview – again potentially colouring their and their parents' experiences and reflections on their epilepsy and its care. If a child's accounts of their epilepsy had

been made at the time of regular seizure activity (before the anniversary of their diagnosis), it is possible their experiences offered in their interviews may have been different. Yet, I do not consider these to be limitations as such, rather a consideration to bear in mind when reflecting on the conclusions that can be drawn from the research. Overarching themes and points of consideration could also transfer to situations of similar context, such as those with other childhood chronic conditions that can appear to be relatively invisible to the wider public (e.g. asthma, diabetes, rheumatoid arthritis, HIV).

Reflecting on a further limitation, the study did not explicitly set out to explore different socio-economic statuses and ethnicities. The lack of ethnic diversity of the sample meant no such differences could be reliably identified or explored. Yet, by not drawing attention to such structural differences, particularly social status, I have not examined a potentially core influence on how children conceptualise, experience and are involved in their epilepsy care. Practical constraints of managing and analysing the substantial quantities of data generated meant that the socio-economic status of children and parents was not explored in sufficient depth to discuss as part of the findings. Future research should consider these societal nuances in further explorations to assess their influence on experiences of childhood epilepsy and children's conceptualisations of care.

In considering the data collection process, more directed and probes around support and information needs for children may have enhanced the quality and quantity of data obtained around these topics. Although, it was acknowledged that such topics could be challenging for children to engage with (i.e. unable to discuss information needs, if they are unaware of what they do not necessarily know). Similarly, the discussions around negotiation were also thinner compared to other aspects of the data. This could also be due to it being harder to articulate such matters through interviews. While the 'magnetic family and friends' ranking exercise did explore this, I feel that I could have promoted more discussion around how the care roles were identified and whether they were altered. Finally, the inclusion of parents in the study was to explore how they helped shape children's experiences and involvement in care, despite this immense value, it would have been interesting and add to the wider discussions of care constructions to have delved further into parents' conceptualisations of childhood epilepsy care at a greater theoretical level.

4.2 Future Research Directions

The research conducted has brought to light additional areas that would benefit further future research. The continued neglect of siblings' involvement in care and significantly in the context of childhood chronic illness has been unresolved. The findings from this study illustrated the role of siblings in children with epilepsy treatment and management regimes and the importance of this role for children with epilepsy, further supporting the need for further research on this contribution. Likewise, future research should consider examining the experiences and perceptions of others connected to the child with epilepsy, such as grandparents, friends, and teachers. This insight could provide a different perspective of epilepsy, and the stigma and 'being different' aspect of children's accounts of epilepsy as illustrated in this study.

Furthermore, children's epilepsy and their treatment and management were not just experienced within the home or the clinic, future research should consider examining other contexts and environments children inhabit. This could include, but should not be limited to, schools and extra-curricular activities, to explore how children engage with their condition and its management in these alternative contexts. Future research may also wish to explore in more depth, children's diagnosis of childhood epilepsy (and related contexts) with particular regard to the information shared with and to them by parents and healthcare professionals.

Changes and developments in healthcare provision, such as those emerging through genetics and personalised medication, may also be of interest to explore with regards to its implications for children and children's involvement in healthcare and its connected decision making. These new treatments and provisions of healthcare offer new avenues to explore agency and perceived competencies, further testing sociology of childhood constructions and conceptualisations.

More theoretically, future research should seek to unpick the nuances of the concept of interdependency specific to child-parent caring relations. Interdependency as a concept has been shown to be more nuanced than has previously been detailed in adult-adult caring relations, with children's perspectives offering a different view on interconnected and interwoven care dynamics. Additionally, the sociological concepts

of normalisation and biography could be more directly researched at the point of a childhood epilepsy diagnosis, due to the instability and perceived threats to children's and parents' lives (Emiliani et al, 2011). This could be achieved through a longitudinal designed research study explaining the transitions between non-controlled, newly diagnosed childhood epilepsy through to well-controlled seizure-freedom and the removal of treatment. These transitions over the course of childhood epilepsy could be 'hot-spots' for changes to routines and senses of self.

4.3 Implications for Healthcare Professionals

A required dimension of this doctoral research was to provide feedback for healthcare professionals charged with providing care for children with epilepsy and their parents on involvement, support and engagement. There are a handful of insights from the study that might be of particular value to healthcare professionals and their clinical practice. Although any feedback detailed must be reflected upon with regard to the limitations set out above and not taken as a recommendation, but thoughts for consideration of practice.

Firstly, a core aspect of the study has demonstrated how children have different levels of understanding of epilepsy and that the information they have and are exposed to was very much dependent on their parent's wishes for their understanding. The imbalance in information gained and exposed to may cause issues in children's ability to participate or engage in treatment and management discussions. Additionally, healthcare professionals should be sensitive to the information needs of children with epilepsy, whilst respecting parents potentially different levels of information they wish to be passed on to children. A potential solution could be to provide epilepsy-related information in different formats, not just leaflets, which engage children in a manner that is unthreatening, engaging, and not dependent on the stage of the condition they are at. For example, an easily accessible animation about epilepsy that provides information about the condition, seizures and medication could be valuable.

Secondly, a further insight indicated how children's and parents desires to integrate with their peers and live as normally as possible despite an epilepsy diagnosis, understanding and appreciating this desire might help and enable healthcare professionals to reinforce this approach. However, this must be reflected upon

alongside the awareness of the potential discord that was seen to be created when attempting to assimilate with a normal childhood and way of life, and the potential stigmatising consequences of not truly fitting this norm. The feelings of 'being different' were apparent so must not be minimised in attempting to ensure a 'normal' life is maintained. Connectedly, children and parents' frames of reference regarding childhood epilepsy care and what it means in terms of living with epilepsy are lacking and further reinforce the need to be 'normal' whilst emphasising their differences. Being exposed to opportunities to explore this difference through having conversations with other children and parents in similar situations should be promoted and encouraged to break down the stigma of being different. An informational resource, such as an animation (as discussed above), could also prove a useful tool for children, teachers, and others to encourage conversations around having epilepsy and what it means, reducing the stigma around the condition.

Thirdly, within clinic appointments healthcare professionals may wish to reflect on the level of communication, and involvement and the style of the interactions being offered and accepted by children and parents. Healthcare professionals should be aware of coalitions that can inadvertently form during clinic appointments between themselves and parents / children, potentially isolating the other from being involved or heard. Reflecting on these aspects can ensure that children who wish to be actively involved are encouraged to be and are not restricted by communication or engagement barriers (e.g. parents not providing them with the chance to speak).

Connected to this, healthcare professionals should acknowledge the legitimacy of children's views and need to move away from themselves as the 'only' experts in child health acknowledging the experiential expertise and understandings of children (Brannen and Moss, 2003). This could be achieved through actively listening to children's contributions, engaging them using the words, phrases and metaphors they use to explain/describe their epilepsy and seizures. As well as ensuring that where a second perspective (from parents, for example) is required, different questions are used, and that children are still included in the discussion and in any and all decisions regarding their care. Additionally, appreciating children may change their levels of involvement over time and in different circumstances and discussions is also important. Awareness of these aspects can ensure that all participants are involved in the appointment as much or as little as they wish.

Finally, healthcare professionals should consider the potential issues that may arise in regard to the home-based treatment and management. In particular, attention should be paid to the differing appreciations of risks between parents and children, and regarding children's potential struggles with medication taking. Problems may only emerge after a considerable period of time and discomfort. Thus, having healthcare professionals speak about potential struggles and strategies around taking medication, prior to problems being raised, may prevent children experiencing distress. Further informational support could also be provided to children regarding taking their medications and epilepsy more broadly, beyond the immediate diagnosis period.

5. Conclusion

In conclusion, this doctoral research has explored children's experiences of childhood epilepsy and their involvement in their epilepsy associated care. Through scrutinising children's own accounts, this research has illustrated how children with epilepsy enact agency through their involvement (or resistance) in epilepsy care, and how parents and healthcare professionals provide a mediating influence on this. It furthers sociological and clinical discussions on, and highlights, children's contributions to their care in the context of childhood epilepsy.

**Children's Experiences of and Involvement in the Treatment
and Management of their Epilepsy: A Qualitative Study**

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References & Appendices

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Appendices

1.A. Children Information Sheet



Childhood Epilepsy – Your Experiences

Hello!

My name is Becky and I am a student at the University of Edinburgh. As part of a study I am contacting children with epilepsy like you, to ask about your experiences of having epilepsy, who looks after you, your doctors and nurses, your care, medicines and anything else you think is important.

This is me ->



To find out more about this - I would like to talk to you about your feelings and thoughts about your epilepsy, what you think about taking medicines and visiting the epilepsy clinic.

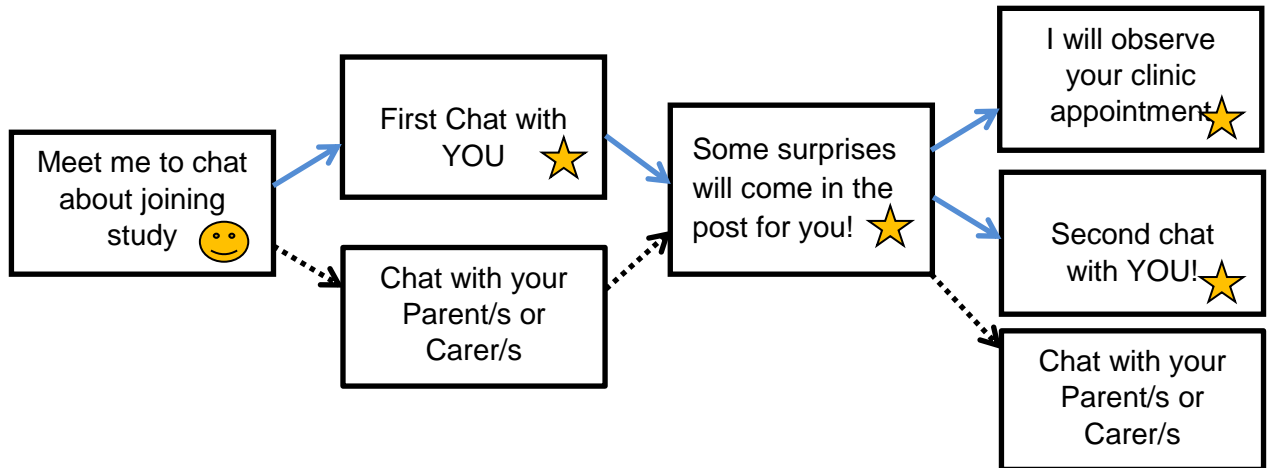
What would you have to do?

I would like to come to your house and chat with you. Of course I will make sure this is ok with your parents or carers first. I have some activities I would like to do with you as well – things like playing a magnet game, making a spider diagram and drawing.

I will come to the hospital with you to watch you and your doctor or epilepsy nurse talking. But I will sit in the corner and not interfere or talk to you during

this. Your doctor/ nurse will know I am coming. Afterwards we will have a chat about happened when you met the doctor and do another fun activity.

This is a picture of what will happen and when –



What will happen to your answers and things you make?

I will use all of the things we talk about including the pictures you make for my study. I will use a voice recorder to record what we talk about and I will take the pictures you draw with me (I can give these back to you if you would like afterwards).

Everything you say will be treated as confidential by me. Confidential means that I might use some of your exact words in my report, but I will not use anyone's real name. You can tell anyone you like about what we talk about and do, but I will not talk to your parents or carers or anyone else you know about what you have told me.



The only time when I would have to tell someone what you said is if I think you or someone else might be getting hurt in some way. I would talk to you about it first though.

What will happen after the visits?

After I have visited, I will send you a leaflet containing some of the things I find out. I will also destroy all of the information I kept about you, including the recordings and notes I make. This will happen after 2 years.

Do I have to take part?

No you don't have to take part if you don't want to. If you do want to take part you can change your mind and say no at any time, even when I am at your house. No one will be upset if you change your mind.



What if I am not sure?

It is a good idea to talk to your mum or dad about this. You can also ask me anything about this now, or ask your parent/s or carer/s to ask me and if you want to take part you can ask me as many questions you want at any time.



Thank You!

Becky

1.B. Children consent sheet




Childhood Epilepsy - Your Experiences

Unique Participant ID:

Consent Form

I agree to take part in Becky's study,

 Tick the box!

- I understand what I will be asked to do
- I understand that everything I say will be recorded
- I understand that the recordings made will be destroyed after use
- I understand that I can stop at any time
- I am happy for Becky to tell my doctor that I am speaking to her
- I am happy for my medical records to be checked during the study by my doctor only.

If you understand the statements above, you now need to decide whether you would like to take part in the project.

I have decided that (Tick the box) –

I **do not** want to take part

I **do** want to take part

Name: Date.....

Becky's Signature: Date:

(Original to be retained by researcher, copy to be retained by the participant)

1.C. Parent initial information sheet



Dear Parent/Caregiver,

Research Study – Childhood Epilepsy and Care: A Qualitative Study

We would like to invite you and your child to take part in the above research study. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with other members of your family. Please contact us if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Purpose of the Study

I am currently carrying out research for a PhD at the University of Edinburgh. As part of the PhD I am researching children's experiences of epilepsy and their involvement in care.

I am interested in exploring children's understanding of epilepsy and how it impacts on their everyday lives, and their involvement in their care. I also will be looking at how children are involved in the management of their epilepsy in both formal and informal healthcare settings.

Why Have My Child and I Been Invited to Take Part?

You have been invited to take part in this study, as you have a child aged between 7-11 years, with a diagnosis of active epilepsy (on antiepileptic medication and/or has experienced a seizure in the last 12 months), and attend the Seizure Clinic at the Sick Kids Hospital Edinburgh.

Do We Have to Take Part?

No, it is up to you to decide whether or not to take part. Taking part in the study is completely voluntary. Your decision to take part in this study will not affect the care or treatment your child is given or receives.

If you and your child do decide to take part, we will meet with you both to talk about the study so you both know exactly what taking part means. After this you will be given an information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

If anything happens which means that you or your child can no longer give consent to take part in the study, you will be withdrawn from it. We would talk to you about this first, where possible.

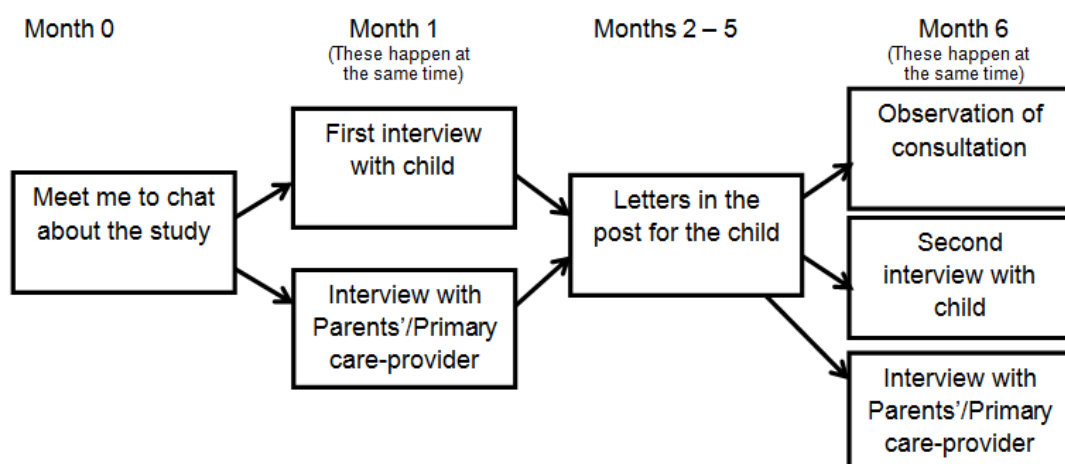
Any data collected before leaving the study would be kept and included, but would still be kept confidential and anonymous.

What Will Happen if We Take Part?

The study involves two interviews with your child (at different times), four short home-based activities (that will be posted to you), an interview with yourself (or another primary care-provider), and an observation of your next consultation at the hospital. During the observation I will sit in the corner and not interfere or talk to during the appointment. Your doctor/ nurse will know I am coming. The second interview with your child will happen after this, where possible.

The interviews with your child and the interview with yourself will take place at your house (or another agreed location) at a time that's best for you. Each interview will take no longer than 40 minutes. The observation will take place during your next consultation appointment at the Sick Kids Hospital.

To keep in touch between the interviews I will also send a few letters to your child. These will just be short notes to say hello and will contain some fun stickers as a thank you for taking part.



This is the order everything will happen in and when they will happen (roughly).

What Will Happen With What My Child and I Tell You?

All of the interviews will be digitally recorded and later written up into text form by Becky Parry (lead researcher). Handwritten notes will be taken during the observation. Your and your child's names and anything else that could identify you will be removed as the recordings are written into text form. The recordings will be destroyed straight after this but the written up files will be kept for this and other related studies.

When we write our findings of the study, we may use your own words as examples but you or your child will not be recognisable. A unique code will be used to ensure your data and contact details cannot be linked.

All information will be treated confidentially. The only exception to confidentiality is if information is revealed that affects your safety or the safety of another family member. We would need to take action, but we would talk to you about this first, where possible.

The consultants at the Sick Kids Hospital (Edinburgh) will not have access to any of the data gathered, unless concerns are raised. Again we would talk about this before, if this needed to happen.

What are the Possible Disadvantages and Risks of Taking Part?

This study is exploring your and your child's experiences of epilepsy which can be a sensitive topic. I do not want to upset either you or your child, so you will both be able to stop the interview or not answer certain questions if you want to.

What are the Possible Benefits of Taking Part?

There are no direct benefits to you or your child taking part in this study, but the findings from this study may help doctors, teachers, and parents' understand children's experiences of epilepsy. This study may also help in developing better healthcare for other children with epilepsy.

You and your child will also receive a small, non-monetary, thank you gift (e.g. a gift voucher).

What happens after the Study is finished?

Once the whole study has been completed the overall findings (without identification of individuals) will be distributed in specialist journals, in the press, and on websites such as the *Scottish Paediatric Epilepsy Network* website (<http://www.spen.scot.nhs.uk>) and the *Muir Maxwell Epilepsy Centre* website (<http://www.edinburghneuroscience.ed.ac.uk/MuirMaxwellCentre/>).

You would be very welcome to a copy of the full report, but a summary of findings will be automatically posted to you once the study has finished.

Further Information

This study has been passed by the NHS Research Ethics Committee as well as the University of Edinburgh, Research and Research Ethics Committee.

If you would like to contact a member of the research team regarding this study or if you have any questions, please contact Becky Parry (R.E.Parry@sms.ed.ac.uk / 07882857369) or Dr Richard Chin (RChin@staffmail.ed.ac.uk).

If you would like to contact a person not directly involved in the research project to seek general advice about taking part in research, you can contact:

Professor Jürgen Schwarze
Head of Child Life and Health
Jurgen.Schwarze@ed.ac.uk
0131 536 0801

If you would like to contact a person not directly involved in the research project but who can provide further details about this specific research project, you can contact:

Dr. Paul Eunson,
Consultant Paediatric Neurologist
paul.eunson@luht.scot.nhs.uk
0131 536 0727

If you wish to make a complaint about this study, please contact NHS Lothian:

NHS Lothian Complaints Team,
Waverley Gate, 2nd Floor,
2-4 Waterloo Place,
Edinburgh,
EH1 3EG
0131 465 5708

If you and your child are interested and would be happy for Becky Parry (lead researcher) to speak to you further about taking part in this study then please complete the Opt-In Form attached. Becky will then contact you to arrange a time to talk about the study some more, you can decide then or at a later point if you want to take part.

Thank you for taking the time to read this information sheet.

Thank you very much!

Becky Parry

PhD Researcher
University of Edinburgh and the Muir Maxwell Epilepsy Centre
R.E.Parry@sms.ed.ac.uk
07882857369

Dr Richard Chin,
Senior Lecturer and Director of the Muir Maxwell Epilepsy Centre
Child, Life and Health
University of Edinburgh

Dr Jeni Harden,
Senior Lecturer
Centre for Population Health Sciences
University of Edinburgh

Dr Martyn Pickersgill,
Senior Research Fellow
Centre for Population Health
Sciences
University of Edinburgh

1.D. Parents information sheet



Dear Parent/Caregiver,

Research Study – Childhood Epilepsy and Care: A Qualitative Study

We would like to invite you and your child to take part in the above research study. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with other members of your family. Please contact us if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Purpose of the Study

I am currently carrying out research for a PhD at the University of Edinburgh. As part of the PhD I am researching children's experiences of epilepsy and their involvement in care.

I am interested in exploring children's understanding of epilepsy and how it impacts on their everyday lives, and their involvement in their care. I also will be looking at how children are involved in the management of their epilepsy in both formal and informal healthcare settings.

Why Have My Child and I Been Invited to Take Part?

You have been invited to take part in this study, as you have a child aged between 7-11 years, with a diagnosis of active epilepsy (on antiepileptic medication and/or has experienced a seizure in the last 12 months), and attend the Seizure Clinic at the Sick Kids Hospital Edinburgh.

Do We Have to Take Part?

No, it is up to you to decide whether or not to take part. Taking part in the study is completely voluntary. Your decision to take part in this study will not affect the care or treatment your child is given or receives.

If you and your child do decide to take part, we will meet with you both to talk about the study so you both know exactly what taking part means. After this you will be given an information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

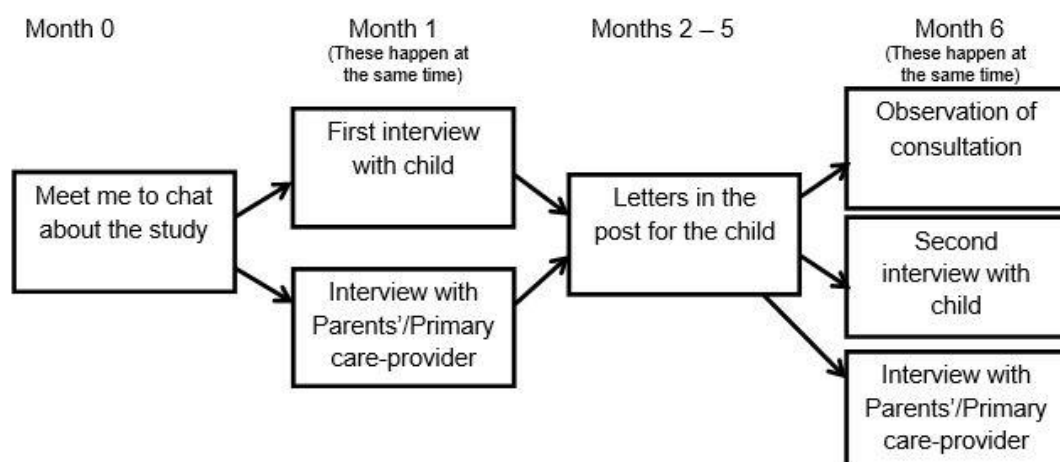
If anything happens which means that you or your child can no longer give consent to take part in the study, you will be withdrawn it. We would talk to you about this first, where possible. Any data collected before leaving the study would be kept and included in the study, but would still be kept confidential and anonymous.

What Will Happen if We Take Part?

The study involves two interviews with your child (at different times), four short home-based activities (that will be posted to you), an interview with yourself (or another primary care-provider), and an observation of your next consultation at the hospital. During the observation I will sit in the corner and not interfere or talk to during the appointment. Your doctor/ nurse will know I am coming. The second interview with your child will happen after this, where possible.

The interviews with your child and the interview with yourself will take place at your house (or another agreed location) at a time that's best for you. Each interview will take no longer than 40 minutes. The observation will take place during your next consultation appointment at the Sick Kids Hospital, with the second interview with your child and yourself happening after this, where possible.

To keep in touch between the interviews I will also send a few letters to your child. These will just be short notes to say hello and will contain some fun stickers as a thank you for taking part.



This is the order everything will happen in and when they will happen (roughly).

What Will Happen With What My Child and I Tell You?

All of the interviews will be digitally recorded and later written up into text form by Becky Parry (lead researcher). Handwritten notes will be taken during the observation. Your and your child's names and anything else that could identify you will be removed as the recordings are written into text form. The recordings will be destroyed straight after this but the written will be kept for this and other related studies.

When we write our findings of the study, we may use your own words as examples but you or your child will not be recognisable. A unique code will be used to ensure your data and contact details cannot be linked.

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The consultants at the Sick Kids Hospital (Edinburgh) will not have access to any of the data gathered, unless concerns are raised. Again we would talk about this before, if this needed to happen.

What are the Possible Disadvantages and Risks of Taking Part?

This study is exploring your and your child's experiences of epilepsy which can be a sensitive topic. I do not want to upset either you or your child, so you will both be able to stop the interview or not answer certain questions if you want to.

What are the Possible Benefits of Taking Part?

There are no direct benefits to you or your child taking part in this study, but the findings from this study may help doctors, teachers, and parents' understand children's experiences of epilepsy. This study may also help in developing better healthcare for other children with epilepsy.

You and your child will also receive a small, non-monetary, thank you gift (e.g. a gift voucher).

What happens after the Study is finished?

Once the whole study has been completed the overall findings (without identification of individuals) will be distributed in specialist journals, in the press, and on websites such as the *Scottish Paediatric Epilepsy Network* website (<http://www.spen.scot.nhs.uk>) and the *Muir Maxwell Epilepsy Centre* website (<http://www.edinburghneuroscience.ed.ac.uk/MuirMaxwellCentre/>).

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Further Information

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If you would like to contact a member of the research team regarding this study or if you have any questions, please contact Becky Parry (R.E.Parry@sms.ed.ac.uk / 07882857369) or Dr Richard Chin (RChin@staffmail.ed.ac.uk).

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Professor Jürgen Schwarze
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If you would like to contact a person not directly involved in the research project but who can provide further details about this specific research project, you can contact:

Dr. Paul Eunson,
Consultant Paediatric Neurologist
paul.eunson@luht.scot.nhs.uk
0131 536 0727

If you wish to make a complaint about this study, please contact NHS Lothian:

NHS Lothian Complaints Team,
Waverley Gate, 2nd Floor,
2-4 Waterloo Place,
Edinburgh,
EH1 3EG
0131 465 5708

Thank you for reading this information sheet. If you have any questions or are not sure about anything please ask now.

Thank you very much!

Becky Parry

PhD Researcher
University of Edinburgh and the Muir Maxwell Epilepsy Centre
R.E.Parry@sms.ed.ac.uk
07882857369

Dr Richard Chin,
Senior Lecturer and Director of the Muir Maxwell Epilepsy Centre
Child, Life and Health
University of Edinburgh

Dr Jeni Harden,
Senior Lecturer
Centre for Population Health Sciences
Sciences
University of Edinburgh

Dr Martyn Pickersgill,
Senior Research Fellow
Centre for Population Health
Sciences
University of Edinburgh

1.E. Parents consent sheet



Childhood Epilepsy and Care: A Qualitative Study
Consent Form

Unique Participant ID: _____

Please read this form carefully. Write your initials in the boxes.

I confirm that I have read and understood the parent information sheet for the above study and have had the opportunity to consider the information and ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

I understand that the interviews will be recorded, and then written in to text form anonymously. The recordings will be destroyed straight away. Anonymous written files will be kept.

I consent to my GP being notified that we taking part in this study.

I understand that relevant sections of my medical notes and data collected during this study may be looked at by individuals from NHS Lothian and the University of Edinburgh where it is relevant to my taking part in this research. I give permission for those individuals to have access to my records.

I agree to take part in this study

Name:

Signature:

Date:

Researchers' Name:

Researchers' Signature:.....

Date Consent Taken:

(Original to be retained by researcher, copy to be retained by the participant)

Appendix 2 - Interview and Observation Topic Guides

2.A. Interview One with Child

Before the interview

- Remind:
 - o No right or wrong answers, can skip questions and stop at any point.
 - o 'Up and Down Thumbs'
 - o Constraints of confidentiality and anonymity.
 - o Dictaphones
 - o Questions?

Rapport questions – find out more about them, use notes from first meeting – put them at ease.

Experiences/Meanings of Epilepsy

- Can you tell me what usually happens on an average day?
 - o Probe around an average day
 - o How does epilepsy fit in to a normal day? How does having epilepsy effect a normal day? Or does it?
 - o How does having a seizure (or fit, funny turn) change the day? Does it?
- Use Spider Diagram: (a probe for exploring different aspects of the epilepsy experience and the emotions surrounding it). Only if interested
- What does epilepsy mean?
 - o Can you remember when you were first told about epilepsy?
 - Can you tell me about it?
 - o What is it? What happens?
 - o What's a seizure? How do you talk about them?
 - o Probe around knowledge of epilepsy
 - What do they know - do they want to know more?
 - How do they want to be told more? Leaflets, website, verbally, etc.?
 - o Do you take medicines?
 - Do you like taking them?
 - Can you remember the first time you had to take them? What was it like? Look like? Taste like?
 - What do they taste like?
- How does it make you feel?
 - o So how do the seizures make you feel? Do you feel tired? Grumpy? Meh? Happy?
 - o How do you feel afterwards?
 - o Use previous answers to probe.
- Family and Friends?
 - o What do your family and friends think about epilepsy?
 - Is it just a normal thing?

- Do you feel different to your family because of your epilepsy?
 - What about your siblings? Parents? What do they think about your epilepsy?
 - What about with your friends and at school?
 - What do your friends think about it?
- Subtly introduce the idea of the future - What about the future?
 - Will epilepsy affect your future? Probe around the future and the influence epilepsy will have on this?
- Support needs?
- Information needs?

Care Experiences

- Use family and friends magnets (aim is to uncover who is involved in the epilepsy care, their role within the care, and the feelings associated with this). If interested:
 - Personalise the magnets with child's family's names on them.
- Arrange the magnets on the board for family.
 - How do these people help with your epilepsy? What do they do to help you?
 - Seizure care?
 - Who looks after you if you have a seizure at home?
 - What happens when you take your medication?
 - Who helps you take it? Do you do it all by yourself? Do you know what medication you are taking?
 - What happens if you don't take the medication?
 - Probe around parental involvement?
- Arrange the magnets on the board for friends and school.
 - How do these people help with your epilepsy? What do they do to help you?
 - Seizure care?
 - Who looks after you if you have a seizure at school?
 - Do you have medication at school?
 - Who helps you take it? Do you do it all by yourself? Do you know what medication you are taking?
 - What happens if you don't take the medication?
- Subtly introduce the idea of the future - What about the future?
 - Will care change?
- Not interested? Use above as probes to questions.

Comic Book Vignettes

- Three vignettes: a child (Ben) who does not like taking medication, a child (Louise) who decides when to go to bed (child's responsibility), and a parent (Victoria's Mum) who does not let her child (Victoria) play outside with friends in case they have a seizure.
 - What do you think about that story? What about you?
 - What is it like for you?
- Probe around implications of epilepsy on decision-making (any? None? Lots?)
- Ben – A child who does not like taking medication
 - Who has the most to say about your epilepsy medicine?

- How are decisions reached with parents? (Negotiated? Told?)
- Who should make these types of decisions? Who should tell you what to do?
- Louise – A child who chooses when to go to bed
 - What do you think? What about you?
 - Should parents tell the child when to go to bed?
 - How are decisions reached with parents? (Negotiated? Told?)
-
- Victoria – A parent who does not let a child play outside with friends in case they have a seizure
 - What do you think? What about you?
 - What do you think about the child? How do they feel?
 - Do you think the parent is right?
-
- Any questions?

Thank You / Keeping in Touch

- Tell the child that there will be little update letters sent to them in the post every now and again – so they will need to look out for them.
- A small surprise will be in every envelope (sticker set).

2.B. Interview Two with Child

Before the interview

- Remind:
 - No right or wrong answers, can skip questions and stop at any point.
 - 'Up and Down Thumbs'
 - Constraints of confidentiality and anonymity.
 - Dictaphones
 - Questions?

Rapport questions – use notes from first interview (holidays, events?) – put them at ease.

Clinic Appointments

- Imagine you had to tell someone else what happened when you went to the hospital – what would you tell them?
 - Use observation notes to probe areas of interest e.g. engagement, participation, and involvement in decisions.
 - Probe on levels of interest in attending consultation appointment.
 - Probe around un-asked questions and moments of confusion etc.
 - Discuss support needs.

- Pots and beans
 - o Ask child to label the pots with each participant
 - o Using a jar of beans and assorted pots representing the individuals involved in the clinic appointment (child, parent/s, doctor, nurse specialist), prompt child to decide how many beans each pot deserves depending on the individuals' participation in the appointment. Idea is to be very specific instead of focusing on the distribution of the beans.
 - Who speaks the most? Least?
 - Who makes the decisions? How much say?
 - Who asks questions? Who answers?
 - o Discuss choices
 - o Discuss how many beans they would want to have in each pot if they could control the appointment.

- Follow up questions from interview one?

Thank You / Keeping in Touch

- Thank the child for participating.
- Explain that the research has now ended.
- Tell the child that there will be little thank you gift sent to them in the post – so they will need to look out for it.
- Explain the dissemination of findings (timings and content).

2.C. Interview One with Parents

Before the interview

- Remind:
 - o No right or wrong answers, can skip questions and stop at any point.
 - o Constraints of confidentiality and anonymity.
 - o Dictaphones
 - o Questions?

Rapport questions – find out more about them, use notes from first meeting – put them at ease.

Overview

- How long has the child been diagnosed with epilepsy?
- What type of epilepsy does the child have?
- What are their seizures like? How many do they have usually within a day/week/month (frequency of seizures – level of control)?
- Do they have any other co-morbid conditions?

Care Arrangements

- I'm trying to get an idea of what is involved in caring for a child with epilepsy – can you tell me a bit about this?
 - o Can you expand a little on: Medication regimens? Seizure prevention?
 - o Is this contested by the child/siblings? Fought? Negotiated (bargaining)?
 - Are they happy with this?
- How has this changed from the point of diagnosis to now?
- Is this something that you developed with the doctors and nurses at the hospital? Their advice or suggestions?
 - o Suggestions from medical professionals seen as very important?
 - o Would you like to hear more/less suggestions for how to deal with: medication, seizure prevention etc.?

Involvement

- Does your child help out with their care? Like sorting out their own medication? Being aware of seizure preventions themselves?
- Health care policy in Scotland says that “children should be active partners in their own healthcare” – in other words that children should be actively involved in their care at home and in the hospital, visiting the doctor etc.
 - o What do you think about this? Do you think they should be more involved?
 - o How do you think they could be more involved?
 - o Why don't you think they should be more involved?
- Does this depend on how old the child is? When they were diagnosed?

Support and Information Needs

- Do you want to know more epilepsy? The condition etc.
 - o Where would you look for further information if you were interested? What about when your child was first diagnosed – where did you go for information?
 - Websites? Books?
 - o Did any of the doctors or nurses make any suggestions?
 - Have they been useful sources of information?
- What about your child?
 - o Do you think they have enough information? What about support?
 - o Do they ask you questions about their condition, medication? How do you answer them?
 - Do you seek additional support online?
 - Refer to medical professionals?
- Do you think your child is interested in understanding their condition?
- How much do you chat about epilepsy with your child?
 - o Do you chat about it before or after a check-up? All the time?
 - o Are there any resources that you use to help you chat to your child?
 - o Have you had any suggestions from the doctors or nurses about how to chat to them?

Comic Book Vignettes

- Three vignettes: a child (Ben) who does not like taking medication, a child (Louise) who decides when to go to bed (child's responsibility), and a parent (Victoria's Mum) who does not let her child (Victoria) play outside with friends in case they have a seizure.
 - o What do you think about that story? What about you?
 - o What is it like for you?
- Probe around implications of epilepsy on decision-making (any? None? Lots?)
- Ben – A child who does not like taking medication
 - o Who has the most to say about your epilepsy medicine?
 - o How are decisions reached with parents? (Negotiated? Told?)
 - o Who should make these types of decisions? Who should tell you what to do?
- Louise – A child who chooses when to go to bed
 - o What do you think? What about you?
 - o Should parents tell the child when to go to bed?
 - o How are decisions reached with parents? (Negotiated? Told?)
- Victoria – A parent who does not let a child play outside with friends in case they have a seizure
 - o What do you think? What about you?
 - o What do you think about the child? How do they feel?
 - o Do you think the parent is right?
- Any questions?

Thank You / Keeping in Touch

- Tell parents that there will be little update letters sent to the children in the post every now and again – so they will need to look out for them. They will always have MMEC sticker on them.
- A small surprise will be in every envelope (sticker set).

2.D. Interview Two with Parents

Before the interview

- Remind:
 - o No right or wrong answers, can skip questions and stop at any point.
 - o Constraints of confidentiality and anonymity.
 - o Dictaphones
 - o Questions?

Rapport questions – use notes from first interview (holidays, events?) – put them at ease.

Clinic Appointments

- Did you do any preparation for the appointment today? Chat to your partner about it? Chat to your child about what was going to happen?
- How did you find that appointment?
 - o Usual?
 - o How did you find the clinicians?
- Probe around the discussions had
- What about child? How do you think they found it?

- Have you ever come across or experienced any government support for your child's epilepsy? Such as policy or legislation?

- Follow up questions from interview one?

2.E. Observation of Clinic Appointment

Focus is on the child's involvement and decision-making within the appointment.

Brief notes will be taken surrounding the following key questions:

- How engaged is the child as they come in to the room?
- How engaged is the child encouraged or discouraged to be?
 - o Who is facilitating engagement or discouraging engagement?
- What level of interaction is there between the individuals' in the room?
 - o What does this interaction look like?
 - o Who is looking at whom?
- Are attempts made to ensure the child understands what is happening?
 - o How does the child react to what is being said? Does the child react?
- Who asks what to whom?
 - o Where are questions directed? Who answers? How do they answer?
- What information is being discussed?
 - o Who is taking part in the discussion?
- How is information presented? Pitched at what level?

Appendix 3 - Additional Research Tools Used

What does epilepsy
mean?



How does it make
me feel?

Family and friends?

An example of the spider diagram for completion – used in the first child interview.



An illustration of the Magnetic Family and Friends ranking activity tool – children were encouraged to decorate and personalise their magnets. Used in the first child interview.



An illustration of the 'pots and beans' ranking activity – used in the second child interview.

Comic Book Vignettes

Ben's story

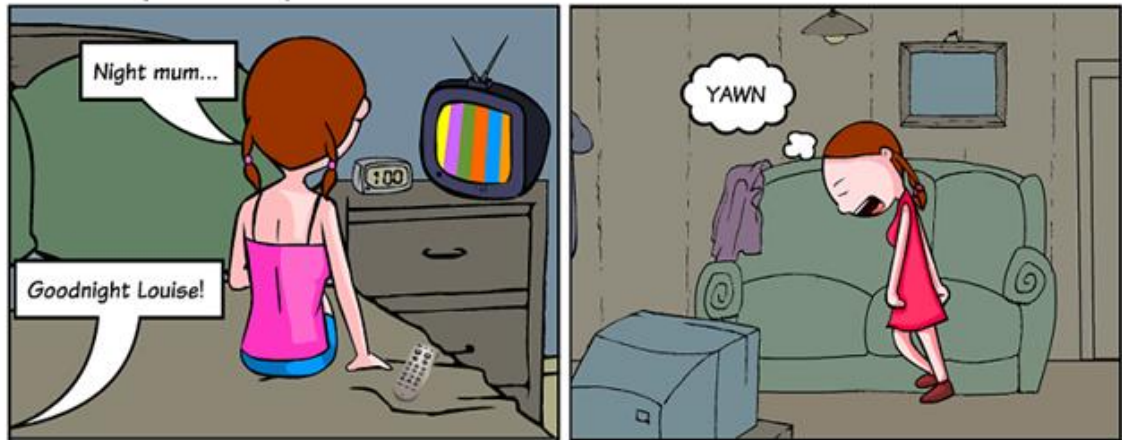


Ben is 8 years old, he has epilepsy. Ben has to take his medication in the morning when he eats breakfast and again in the evening after he has eaten dinner.

But Ben does not like taking his medicines because they make him very sleepy. Sometimes Ben refuses to take his medicines.

Ben's mum and dad sometimes get a little angry when Ben refuses to take his medicines.

Louise's story



Louise is 11 years old, she has epilepsy. Louise chooses when she goes to bed. Sometimes she stays awake very late watching TV in her bedroom.

When Louise has stayed up late at night the next morning she is very tired. When she is tired Louise sometimes has seizures.

Victoria's story



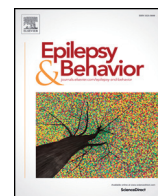
Victoria is 9 years old, she has epilepsy.

Victoria's mum does not like her going outside to play with her friends. Victoria's mum is worried that Victoria might have a seizure and hurt herself where she cannot see.

Victoria is only allowed to play where her mum can see her.

The comic book vignettes used within the first child and parent interviews

Appendix 4 - Published Articles



Review

Families' experiences of living with pediatric epilepsy: A qualitative systematic review



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ABSTRACT

Living with epilepsy in childhood has implications for the child and their family beyond the physical effects associated with epileptic seizures. Qualitative research has emerged, aiming to deliver a greater depth of understanding of the experiences of living with epilepsy from the perspectives of children with epilepsy, their parents, and their siblings. This review of qualitative research had three aims: first, to synthesize the demographic and epilepsy profiles of research participants in eligible studies in order to provide a clear picture of who are included and excluded when studying families' experiences; second, to present and discuss the methodological concerns and implications of research involving children with epilepsy; and third, to synthesize the findings arising from qualitative research with families in order to identify common themes across all relevant studies to date.

Papers published in the English language prior to January 2016 were identified following a search of eight electronic databases: Embase, Psycinfo, Medline, CINAHL, Web of Knowledge, ASSIA, Web of Science, and SCOPUS. Studies were included if they involved a sample of children with epilepsy (up to 18 years of age), parents, or siblings of children with epilepsy and used qualitative methods. Twenty-one studies were identified as eligible for inclusion in the review.

Findings in relation to the three aims were the following: 1) Researchers were seeking an understanding of children's experiences directly from children rather than by parental proxy. However, children with learning disabilities were often excluded from research, meaning that their views are not being heard. Parental research was predominantly with mothers, and father experiences were not often accessed. There was very little research with siblings. 2) The rationale for and ethical implications of the choice of research methods adopted were not always clear, and not all studies gave adequate attention to the development of appropriate methods for research involving children. 3) Two dominant themes emerged across the studies: normalcy and children's agency. Cutting across many of the challenges that living with epilepsy presented was the desire (by parents and children) for a 'normal' childhood. The studies also highlighted that children have knowledge about their own condition and epilepsy more generally and that they are involved in managing the ways in which they cope with epilepsy, both in terms of seizure prevention and managing their relations with others, particularly peers.

Future research should ensure that appropriate design, data collection, and analytic strategies are adopted to facilitate the participation of all family members. Enhancing the quality of the research will, in turn, optimize validity and opportunities for the translation of findings into better health, education, and social practices to improve care for children and their families affected by epilepsy.

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1. Introduction

Living with epilepsy in childhood has implications for the child and their family beyond the physical effects associated with epileptic seizures [1,2]. Utilizing quality-of-life (QoL) measures, research has

demonstrated a detrimental effect on academic achievement, associated with poor behavior management and performance, social isolation, and low self-esteem for children with the condition [3,4]. Parents of children with epilepsy have also been shown, using similar tools, to have higher rates of depression, anxiety, and stress because of the additional burdens and care needs associated with having a child with a chronic illness [2,3].

However, questions have been raised as to whether a quantitative approach can fully capture children's and parents' experiences of living with epilepsy [5,6]. Moreover, children's own views of their epilepsy have often been overlooked in favor of obtaining proxy assessments

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generated by the use of quantitative tools with parents [7–9]. In response, qualitatively led research on the topic has emerged, aiming both to deliver a greater depth of understanding of the experiences of children and their parents and, subsequently, to improve the care provided to these families.

Previous reviews of the qualitative research on this topic [5,10] have applied a QoL lens to the literature, providing insight into how the key QoL domains are affected by pediatric epilepsy. However, a focus on QoL may limit inclusion of relevant literature that has not adopted this approach. In addition, existing reviews, while addressing some issues pertaining to the quality of the research being reviewed, have not presented a detailed analysis and discussion of the research methods used. In this systematic review, we synthesized the findings and methods from all available qualitative research on experiences of living with epilepsy from the perspective of children with epilepsy (cwe), siblings, and parents.

The review had three aims relating to research participants, research methods, and research findings. First, it synthesized the demographic and epilepsy profiles of research participants in eligible studies in order to provide a clear picture of who the studies included and excluded. Second, the review synthesized all findings arising from qualitative research with children, parents, and siblings in order to identify common themes across all relevant studies to date. Third, using standard qualitative research quality criteria and assessment of appropriateness regarding researching with children, this review assesses the methodological approaches and implications of research involving children with epilepsy. By addressing these aims, the review embraced a holistic review of research with cwe and their families which facilitates further understanding of both the findings of research and the manner in which these findings are established.

2. Methods

2.1. Search strategy and study selection criteria

The literature search for the review was conducted between March and December 2014, and then, the same searches were run again January to February 2016.¹ The team held initial discussions to develop the MeSH (Medical Subject Heading) search terms, based on the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) search tool [11] which is specifically designed for qualitative evidence synthesis. We searched the Cochrane Database of systematic reviews, Embase, Psycinfo, Medline, CINAHL, Web of Knowledge, ASSIA, Web of Science, and SCOPUS. Details of the search terms and the combination of searches used are given in Table 1. The inclusion and exclusion criteria for the review related to date, language, study design, population, and study focus (Table 2).

2.2. Methods of the review

The screening process involved several stages (see Fig. 1). First, the databases were searched and duplicates removed. The titles of the papers were reviewed by JH, and where the focus was not clear in the title, the abstract was examined. Those considered relevant based on specific mention of pediatric epilepsy or epilepsy and families in the title or abstract were included. The abstracts of the remaining 160 sources were examined by JH. When the abstract was not descriptive enough or no abstract was available, the full text was examined. Following discussion between JH and RB, 138 sources not fulfilling the

¹ Following the initial search period (Mar–Dec 2014), the paper was drafted but not completed. Subsequently, there was a gap for personal reasons, and the team felt that it was then appropriate to conduct the same search again to ensure that it was as current as possible (Jan–Feb 2016). This second search was carried out using the same terms by the same researcher.

Table 1
Database search strategy.

Databases	Embase, Psycinfo, Medline, CINAHL, Web of Knowledge, ASSIA, Web of Science, and SCOPUS
Sample	parent* OR mother* OR father* OR family OR families OR child* OR adolescent* OR teen* OR young people or sibling*
Phenomenon of interest	epileps*
Design	interview* OR focus group*
Evaluation	view* OR experienc* OR opinion* OR attitude* OR perce* OR belie*OR feel* OR know* OR understand*
Research type	qualitative
Final search strategy	parent* OR mother* OR father* OR family OR families OR child* OR adolescent* OR teen* OR young people or sibling* AND epileps* AND interview* OR focus group* OR view* OR experienc* OR opinion* OR attitude* OR perce* OR belie*OR feel* OR know* OR understand* OR qualitative

inclusion criteria were excluded. Where more than one source utilized the same primary data, the original source was used, resulting in the removal of one further source leaving twenty-one sources (eighteen peer-reviewed primary journal articles and three theses) for inclusion in the review (Table 4).

2.3. Data extraction and synthesis

The following data were extracted for each study: author, year, country or origin, study aims, sample population, research methods, and key findings. From the data extracted, JH synthesized information relating to the study populations: which family members were included; age, gender, socioeconomic status, ethnicity, seizure type and frequency, duration and onset of epilepsy, and study exclusion criteria. Following this, a thematic synthesis of the study findings was conducted [12]. The findings/results, and the information presented on participants and methods from each study, were first read by JH and RB. Initial themes within the findings of each study were identified independently. The initial themes were then compared across the studies, and agreement reached on the synthesis of themes under two broad main headings – impact of epilepsy and coping with epilepsy. Subthemes were identified as the following: physical and emotional impact, impact on everyday activities, impact on social relations, knowledge about epilepsy, prevention of seizures, managing social relations, and support. The final step involved ‘going beyond’ [12] the simple description of the themes and research information in order to present a discussion of the implications of the review findings and any recommendations arising from the review. This was achieved through whole-team discussions.

2.4. Critical appraisal

Alongside the data extraction and synthesis, the quality of the studies included was assessed by JH and RB using established criteria to evaluate the quality of reporting and the appropriateness of the methodology and methods adopted [12]. Given the focus of this review, specific attention, where appropriate, was given to the consideration of issues raised when researching with children. Critical appraisal was not used to exclude articles from the review. As the overview indicates, the quality of the studies was generally high (Table 3). Moreover, it is recognized that, while there are tools to appraise qualitative research, there is not an appropriate empirically tested method for excluding qualitative studies on methodological grounds [12–14]. Appraisal tools “should be utilized as part of a process of exploration and interpretation in the synthesis process” [13]. It is common practice for methodological concerns to be highlighted and presented in the review findings rather than excluding articles from reviews (for an example see [15]). In this review, the appraisal tool was used to highlight methodological issues in relation to reporting and conducting research involving children

Table 2
Inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
Study design	1) Primary research 2) Qualitative methodology (or mixed methods which include qualitative element)	1) Reviews of the literature 2) Quantitative research
Population	1) Children (18 years and under) with epilepsy, their parents, their siblings	1) Studies including both children and adults with epilepsy 2) Studies involving groups with multiple illness
Study focus	1) Children and family experiences of living with pediatric epilepsy	1) Specific epilepsy treatments 2) Epilepsy surgery
Date	1970 to 2016	Pre-1970
Language	English language papers	Non-English language papers

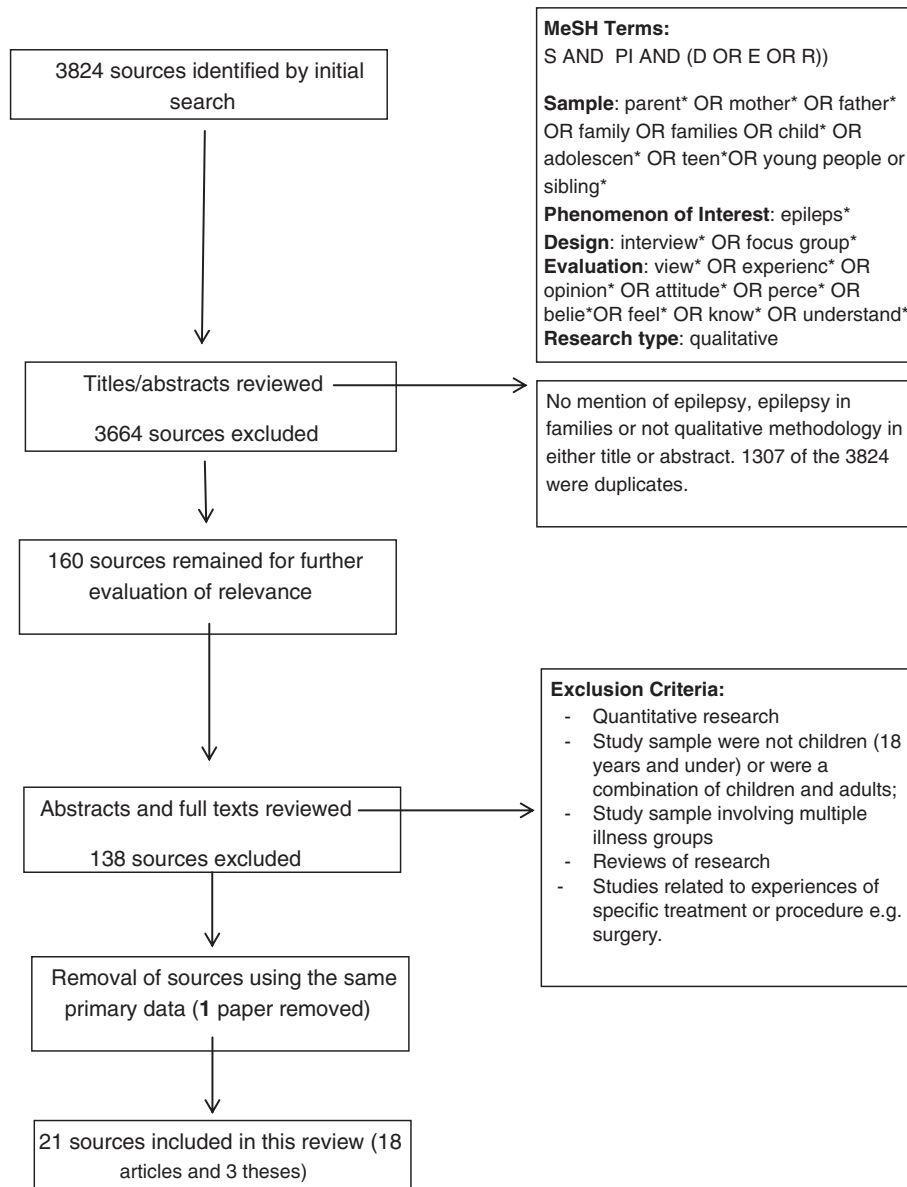


Fig. 1. Flow of identification and selection process.

and families; an overview is presented in Table 3, and further detail is presented in Section 3.3 and Section 4.

3. Results

The results are presented in three sections: research participants, research methods, and research findings.

3.1. Research participants

The following section summarizes the profile of participants included in the studies.

3.1.1. Family members

Ten of the twenty-one sources only included children with epilepsy (cwe) in the research, and a further two included both parents and cwe.

Table 3
Critical appraisal of studies.

	Aims clearly reported	Adequate reporting of sample	Adequate reporting of data collection methods	Adequate reporting of data analysis methods	Appropriate research design	Appropriate recruitment strategy	Appropriate data collection method	Appropriate data analysis method	Researcher–participant relationship considered	Ethical issues considered
Benson et al. [16]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Chen et al. [17]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Eklund & Sivberg [18]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
Elliott et al. [19]	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
Galletti et al. [20]	Yes	Yes	Yes	No	Yes	Yes	Yes	Cannot tell	Cannot tell	Cannot tell
Hames & Appleton [21]	Yes	Yes	No	No	Yes	Yes	Yes	Cannot tell	Cannot tell	Yes
Hightower et al. [22]	Yes	Yes	Yes	No	Yes	Yes	Yes	Cannot tell	Cannot tell	Cannot tell
Jones et al. [23]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Lewis & Parsons [24]	Yes	Yes	Yes	No	Yes	Yes	Yes	Cannot tell	Cannot tell	Cannot tell
Macleod [25]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
McEwan et al. [26]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
McNelis et al. [27]	Yes	Yes	No	No	Yes	Cannot tell	Yes	Cannot tell	Cannot tell	Yes
Moffat et al. [28]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mu [29]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Nguyen [30]	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Cannot tell	Cannot tell
Poyner Reed [31]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
Roberts & Whiting [32]	Yes	No	No	Yes	Yes	Cannot tell	Yes	Yes	Cannot tell	Cannot tell
Ronen et al. [33]	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Cannot tell	Cannot tell
Rushe [34]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Smith et al. [35]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
Wagner et al. [36]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes

Seven studies reported on research with parents/caregivers and one with parents/caregivers and siblings. One study included siblings only.

3.1.2. Age

The age of cwe involved in the research ranged from 6 to 19² years with a mean range of 7.3 years between the youngest and oldest children involved. Siblings included in research ranged from 8 to 18 years, and one was 25 years.

3.1.3. Gender

One hundred thirty-six girls compared with 96 boys were included across the studies. In the studies involving parents, 110 mothers and 38 fathers were included. The gender of siblings was only included in one study (4 boys and 4 girls) [34]. Two studies did not provide data on the gender of the parents involved [31,36], and one did not give information on siblings' gender [21].

3.1.4. Socioeconomic status

Two sources gave information regarding the socioeconomic status of the child participants [19,20]. Of these, one reported their sample to be 82% 'middle' or 'upper' socioeconomic status [19]. The second reported a range with the majority (56%) in the 'category 4' socioeconomic position within a range of seven categories [20]. Two of the sources involving parents gave information on educational level. In both, the majority of parents had college level education or higher [23,30].

3.1.5. Ethnicity

Few studies provided information on ethnicity. In those that did, the majority of participants were reported as being 'White' or 'Caucasian' [19,23,30]. In one study, the participants were mainly 'Black' [22].

3.1.6. Seizure type and frequency

Seven studies did not provide information on seizure type, and two only provided a general indication of the number of child participants whose epilepsy was 'refractory' [19] or 'intractable' [35]. The remainder presented a breakdown of the number of participants according to seizure types: including simple and complex partial, generalized, absence, tonic-clonic, and myoclonic. The frequency of seizures was presented either

quantitatively (by number of times per day/week/month/year) or as a descriptor of frequency, including frequent/daily; sporadic/moderate with an indication of what this meant in quantitative terms, for example, monthly or less than two per year.

3.1.7. Duration/age of onset

Information relating to the time living with epilepsy was presented in a number of ways: duration of epilepsy, age of onset, age at diagnosis, and time since last admission. One study [36] did not present any such information. Across the studies, a broad range of experiences associated with the time living with epilepsy were represented. Age of onset ranged from early infancy (first few months of life) to teenage years with a mean of 5.95 years. Most studies specified a minimum duration of six months since diagnosis and included those living with epilepsy for many years. The mean range for epilepsy duration was 8.9 years.

3.1.8. Exclusion criteria

The most common exclusion criterion across the studies was the presence of significant cognitive impairment, though this was described in different ways, for example, 'developmental delay' [17] or 'mental retardation' [18]. Two studies provided a rationale for this; the limitation that cognitive impairment may present for their participation in interviews [19] and to avoid confounding findings that may not relate directly to epilepsy [16]. Information was not given concerning how such impairment was defined or measured. Some studies excluded other comorbidities including cerebral palsy, autism, and other neurological disorders. Six studies did not provide specific information on exclusions [22,24–26,31,36].

3.2. Main themes

This section presents a synthesis of the themes identified across the studies under two broad headings: the impact of living with epilepsy and coping with epilepsy.

3.2.1. Impact of epilepsy on children and families

Within all the studies, the most commonly reported themes related to the challenges and constraints of living with epilepsy.

3.2.1.1. Physical and emotional impact of living with epilepsy. Several studies with children noted the physical impact of having seizures including

² Although our inclusion criteria set a maximum age of 18 years for the children included in the research, we included one study in which the upper age was 19 years.

the following: injuries [18], muscular pain, and headaches after seizures [17–19]; tiredness or lacking energy following seizures [17,18]; and needing more sleep than an average person their age [19]. The side effects of medication were a common concern. These side effects were reported as making them ‘feel bad’ in a general sense [22,26,28] and more specifically included concerns about excessive tiredness [18,24]; weight gain, particularly among older teenagers [18,24]; and mood changes [28]. Parents and children reported some confusion about whether the side effects, particularly tiredness or behavioral change, were a result of the seizures or the medication [18,36]. Parents reported burnout and exhaustion arising from a number of concerns, including worry [32,35], constant monitoring of their child’s physical and mental health [29,35], challenges of navigating the health care system [23,35,36], and acting as their child’s advocate in health care and education contexts [27,31,32,35,36].

However, it was the emotional rather than physical impact of epilepsy that was more prominent in the studies’ findings. Children with epilepsy reported a range of negative emotions in relation to having epilepsy including feeling troubled [20] and experiencing intermittent sadness or depression [19] as a result of the epilepsy; frustration and anger at having too many seizures, at medication and seizure side effects [19] and at restrictions on their participation in social activities [18,24,29]; and fear about what happens in a seizure and fear that they might die [17,19,20,25,26]. When describing social relations, cwe often reported feeling lonely or isolated [19,26,28] and embarrassment about being seen having a seizure [18–20,22,25,28]. Siblings also reported feeling anxious, sad, worried, and lonely [21] as well as worrying about when a seizure might occur and what might happen during a seizure [34]. Parents reported feelings of uncertainty and confusion [30,32] alongside constant worrying about and monitoring of their child’s physical and emotional health and well-being [29,32,35], including worry that their child might die as a result of a seizure [29] and anxiety about whether seizures would return when they had been seizure-free for a time [29]. Parents also reported frustration at the time and effort they needed to put into finding the information and services they and their cwe required [35]. Despite the overwhelming emotional impact being negative, there were also some positive effects reported by both cwe and parents. Some cwe reported having a sense of pride in coping with epilepsy [20], and others said that it made them special that there was something extra about them that their peers did not have [26]. Some parents referred to their experiences of caring for their child as being part of their ‘personal growth’ [27] and that they felt proud in gaining the expertise and skills required [35].

3.2.1.2. Impact on involvement in everyday activities. Children with epilepsy reported some limitations in their participation in social activities and education as a result of their epilepsy. The kinds of activities which children and young people expressed frustration about not being involved in changed with age: among younger children, not being able to attend sleepovers with friends [22,27,28] or having to interrupt play to take medication [28]; among older teenagers, immediate or future concerns about going to nightclubs [18,28], drinking alcohol [26], and driving [18] were more pressing. The reasons given for these limitations related to both the impact of medication and the need to manage/avoid triggers for their epilepsy, as will be discussed below. Some children reported being restricted in their involvement in some activities by parents [20,26] and by teachers [17,18,20,28]. A lack of self-confidence was also noted as holding them back from engaging in social activities [19]. Siblings reported being limited in their own activities as a result of their parents’ time being taken up with the care of their sibling with epilepsy [21,34]. Findings from the parental research focussed mainly on concerns about or limitation relating to their child’s involvement in social activities rather than the parents’ own experiences. Smith et al. did note that having to care for their cwe led some parents to make additional personal sacrifices, for example, giving up their education [35].

Epilepsy was reported by parents and cwe as having an impact on educational achievement [17,19,25,28,32–34] as a result of problems with concentration and memory and missing lessons [28], particularly when medication changed [32]. Several studies reported that teachers often lacked information about epilepsy and epilepsy-related educational difficulties [24,26,30,35,36] and were uncomfortable dealing with epilepsy [36] or overreacted to seizures [26].

3.2.1.3. Impact on social relations. The theme of ‘being normal’ was often referred to in relation to the impact of epilepsy on social activities and educational achievement. Children with epilepsy described the importance of being seen as the same as everyone else, but many reported feeling different [16,18,20,27] and of not belonging [19]. Having to take medication was reported by some cwe as a physical reminder of that difference [26]. Many of the studies reported cwe experiencing some difficulty making friends [17–19,24,26], stigma, and bullying [16,19,25,26,28]. Parents expressed concern about epilepsy interfering with ‘normal’ childhood. What ‘normal’ meant changed at different ages, for example, concerns in infancy related primarily to the achievement of developmental milestones, but as the child became older, parents also expressed concerns about whether they were able to have a ‘normal’ childhood [27] and a ‘normal’ future as an adult [35].

Studies also reported parents’ concerns about changes to family relationships and roles. Some parents noted that the caregiving responsibility for a child with epilepsy was greater than ‘normal’ parental caregiving [35]. This relates to the sense of constant worry and vigilance noted earlier, but some parents also reported a reframing of the parental role to include more of a health carer role [27,29,31]. One study referred to the impact that parents reported on relationships with friends and with spouses with some attributing marital breakdown to the demands and stresses of caring for cwe [35].

Parents also expressed concerns about the impact of this changed parental role on siblings, in particular, whether siblings were resentful of the limited time they had to give to them [35]. The studies with siblings reported that they did express concern about the limited time with their parents but were also conscious of the caring burden for parents and described their own role in caring for the cwe [21,34]. They also reported changes in their relationship with their sibling (cwe) as a result of the epilepsy. Some reported the cwe’s behavior change as a result of the epilepsy and expressed feelings of loss of their previous relationship [34]. However, siblings also reported feelings of pride and love for their sibling (cwe) [21,34].

3.2.3. Coping with epilepsy. Several dimensions of coping with epilepsy were reported across the studies: knowledge, prevention of seizures, and support.

3.2.3.1. Knowledge about epilepsy. Children with epilepsy reported some knowledge of their condition and of epilepsy more generally. They were able to describe the feelings of their seizures [20,28], had an awareness of their triggers [17,20,22,26], and were able to describe medication names, amounts, and routines [22]. Children with epilepsy also reported the need for others, particularly teachers [24,28], to be made more aware of and knowledgeable about epilepsy to address misconceptions that contributed to the stigma around epilepsy. Benson et al. found that the cwe’s peers associated epilepsy with intellectual impairment because there was something ‘wrong’ with their brain [16]. In contrast to the perceived need to educate others, cwe did not express the need for more knowledge about their condition; only one study mentioned information searching as a form of coping with epilepsy [18]. Nevertheless, some cwe reported difficulty in explaining epilepsy to others [16], and there were reported gaps in their knowledge; some confusion about medication particularly in the context of comorbidity [24] and a lack of knowledge about the causes of epilepsy [16], epilepsy types, and legislation [26]. Parents’ accounts emphasized the importance of learning about epilepsy as a way to cope with their caregiving

Table 4
Articles included in the review.

Lead author, year	Location	Aim of the research	Sample	Qualitative methods and analysis	Main findings
Benson, 2015	Ireland	To identify the contextual factors that act as challenges for cwe when disclosing their epilepsy diagnosis to others external to the nuclear family	N = 29 Aged 6–16 years 17 female, 12 male Duration of epilepsy: 0.17–10 years (mean 3.87 years) Medication: 28 on at least one AED Seizure type: 19 had multiple types. Complex partial (10); simple partial (4); tonic–clonic (19); tonic (5); absence (14); atonic (4); myoclonic (6); ESES (1) Seizure frequency: 58.6% had seizure in 4 weeks prior to interview. Exclusions: children with intellectual disability, developmental delay, significant learning or behavioral deficits and/or other significant medical conditions.	Semistructured interviews with children. Thematic analysis.	The five main challenges to epilepsy diagnosis disclosure for children were the following: 1) cwe's desire for normalcy, 2) out of sight but in the mind, 3) contending with negative responses to disclosure, 4) the complexity of epilepsy, and 5) self and others' perceptions of epilepsy.
Chen, 2010	Taiwan	To explore the lived experiences of children with epilepsy in Taiwan	N = 15 Aged 7–12 years 10 female, 5 male Duration of epilepsy: 12–96 months (mean 3.4 years) Medication: all on at least one AED. Seizure type: no information Seizure frequency: 50% no seizures in previous month; 20% had had 1–9 seizures. Exclusions: those with developmental delay or uncontrolled epilepsy	Semistructured interviews with children. Phenomenological analysis	Taiwanese children with epilepsy had similarly lived experiences as their counterparts in Western culture, e.g., unpleasant somatic symptoms, difficulty learning, and troubled peer relationships. Taiwanese children also coped similarly with epilepsy by taking medications to control seizures, but they differed from their Western counterparts in trying to self-manage seizures and seeking support from family members.
Eklund, 2003	Sweden	To describe the lived experience of adolescents with epilepsy and their coping skills	N = 13 Aged 13–19 years 10 female, 3 male Duration of epilepsy: 1–5 years (7); 6–10 years (2); >10 years (4) Medication: all on at least one AED. Seizure type: absence (5); generalized (8) Seizure frequency: Several per month (3); Several per year (4); less than 2 per year (6) Exclusions: those with mental retardation or cerebral palsy	Semistructured interviews with children. Content analysis	Adolescents experienced strains from seizures, limitation of their leisure activities, side effects of medication, and feelings of being different. They had developed coping strategies including finding support, being in control, and experimenting.
Elliott, 2005	Canada		N = 49 Aged 7–18 years 25 female, 24 male Duration of epilepsy: information not given. Medication: all but one were on at least one AED. Seizure type: medically refractory Seizure frequency: information not given. Exclusions: younger than 7 or older than 18 years; location; impaired cognitive or language skills that limited the child's ability to participate in the interview	Semistructured interviews with children. Grounded theory analysis.	Epilepsy has a negative impact on children and adolescents' quality of life: physical—excessive fatigue is a barrier to academic and social pursuits; emotional/behavioral—intermittent emotional distress is heightened by epilepsy-related factors such as unpredictability of seizures; social—profound social isolation; and cognitive/academic—participants described discontinuous, fragmented learning. Youths perceive seizures as the major barrier to their sense of normalcy, setting them apart from others.
Galletti, 1998	Italy	To explore the experiences of children and adolescents with epilepsy	N = 41 Aged 7–18 years Duration of epilepsy: information not given. Time since admission 0–18 years. Medication: all on at least one AED. Seizure type: focal (25); generalized (16) Seizures frequency: time since last seizure – recently (19); more than six months (7); more than 1 year (15) Exclusions: those with abnormal neurological and cognitive development or other severe comorbidity	Semistructured interviews with children. Categorization and correlation with seizure type.	Children aged 7 or older were able to describe the experience of partial seizures. Social status and school achievement had no significant influence on the patient's ability to express his or her feelings, but some children found it difficult to describe experiences.
Hames, 2009	UK	To assess siblings' response to having a brother or sister with epilepsy and to develop information for them	N = parents (25); siblings (14) Age of siblings: 8–18 years (13) 25 years (1) Duration of epilepsy: 3–15 years (mean = 6) Medication: all on at least one AED. Seizure type: generalized (14)	Semistructured interview with parents and sibling. Written personal account by sibling. Thematic content analysis.	Siblings' accounts included negative feelings about the impact having a brother or sister had on their lives and that of their parents and about their worries for their sibling. The accounts also expressed positive statements about feelings of care and love for their sibling. Information for siblings had not been received by any of the families.

Hightower, 2002	USA	To gain a better understanding of children's experiences with epilepsy	Seizure frequency: none had experienced more than 30 days seizure-free in preceding 6 months. Exclusions: siblings under age 5 or siblings who also had epilepsy or other serious medical conditions N = 8 Aged 9–12 years 3 female, 5 male Duration of epilepsy: at least 1 year. Medication: all on at least one AED. Seizure type: generalized tonic–clonic (4); absence (2); partial (2) Seizure frequency: no information given Exclusions: no information given	Semistructured interviews with children. Thematic analysis.	Children with epilepsy dislike having seizures and taking seizure medication; friends provide significant relationships and support; children with epilepsy participate in sports; and children with epilepsy are cognisant of auras and ways to prevent seizures.
Jones, 2014	USA	To develop a theoretical framework for person-centered care models for children with epilepsy and their parents	N = 22 Age of cwe: 9–18 years 11 female and 11 male (cwe) 17 female and 5 male (parents) Duration of epilepsy: mean 5.57 years Medication: no AED (5); one AED (14); more than one AED (3) Seizure type: focal (8); generalized (14) Seizure frequency: all had 1–several seizures (less frequently than monthly) per year. Exclusions: cwe over 18 years	Semistructured interviews with parents. Grounded theory analysis.	A theory composed of three zones (Zones 1, 2, and 3) was devised that can be used to conceptualize parents' viewpoints. Zone location was based on a parent's perspectives on their child's comorbidities in the context of epilepsy. The zones are based on how the parents describe (a) their concerns about the child's struggles and (b) their understanding of the struggles and (c) the parent's view of the child's future. The zones help clinicians conceptualize and build a framework within which to understand how parents view their child's struggles, which influences the parents' ability to understand and act on clinician feedback and recommendations.
Lewis, 2008	UK	To understand the experiences of children with epilepsy in mainstream education	N = survey (44); interviews (22) Aged: survey (3–23 years); interviews (6–17 years) 13 female, 9 male Duration of epilepsy: >1 year–14 years. Medication: at least one AED (15); none (5); no information (2) Seizure type: no information given Seizure frequency: less than 6 months (3); 6–12 months (2); 1–2 years (2); more than 2 years (4) Information not give or unclear (11) Exclusions: no information given	E survey and semistructured interviews with children. Thematic analysis.	Children and young people were clear about the nature of their condition. There was reluctance in accepting epilepsy as 'part of them' and feelings of shame and secrecy were reported. Children reported feeling 'different' because of their epilepsy.
MacLeod, 2009 (Phd thesis)	USA	To determine whether or not elements of stigma were present in narratives about participants' day-to-day living	N = 4 Aged 13–18 years 4 female Duration of epilepsy: no information given Medication: at least one AED Seizure type: no information given Exclusion criteria: no information given	Repeat interviews with children (×3). Phenomenological and narrative analysis.	Themes 1) I Am Like Everyone Else (Except for my Seizures); 2) There are Worse Things than Epilepsy; 3) My Parents Trust Me; 4) Am I Having a Seizure?; 5) Bullying Because of Seizures; 6) Bullying Because of Something other than Seizures; 7) Coping with Bullying; 8) Academic Difficulties; 9) Disclosure Management; 10) Seizures are Scary to Have and to See; and 11) If I have a Seizure, Don't Attract Attention to Me!
McEwan, 2004	UK	To investigate quality of life (QoL) from perspective of adolescents with epilepsy and explore changes in QoL issues in progression towards adulthood	N = 22 Aged: 12–18 years 16 female, 6 male Duration of epilepsy: time since diagnosis ranged from 1 month–13.5 years (mean = 7 years). Medication: all but one were on at least one AED Seizure type: simple partial (9); complex partial (5); generalized (16); myoclonic (1) Seizure frequency: daily (6); weekly (2); monthly (6); 2–6 months (4); 6–12 months (3); less than once per year (1) Exclusions: those with deteriorating neurological health; those with nonepileptic seizure disorders; those with significant learning difficulties	Focus groups with children. Thematic analysis.	The study identified two main themes comprising (a) issues related to adolescent development (identity formation) and (b) epilepsy-related variables. The main issues related to peer acceptance and development of autonomy. No significant age-related differences in issues were identified.
McNelis, 2007	USA	To explore the self-reported concerns and needs of children with epilepsy and their parents	N = 11 (children); 15 parents Aged: 7–15 years 5 female, 6 male (children) 12 female, 3 male (parents) Duration of epilepsy: 18 months–5 years Medication: all were on at least one AED Seizure type: generalized tonic/clonic; absence, complex partial, simple partial	Focus groups with children. Focus groups with parents. Thematic analysis.	Themes emerging from the child data included the need for clinicians to 'talk at my level' and 'feeling different from others'. Parents highlighted the difficulties and struggles of caring for a child with epilepsy and the need for information to be provided at the appropriate time.

Table 4 (continued)

Lead author, year	Location	Aim of the research	Sample	Qualitative methods and analysis	Main findings
Moffat, 2009	UK	To investigate children's perceptions of the impact that epilepsy has on their quality of life	Seizure frequency: no information given Exclusions: no information given N = 22 Aged 7–12 years 11 female, 11 male Duration of epilepsy: 1–9 years Medication: 20 of the 22 children were on at least one AED Seizure type: simple partial (6); complex partial (5); generalized tonic-clonic (7); absence (7) Seizure frequency: daily (3); weekly (3); monthly (5); several times a year (7); once a year (2); seizure-free (2) Exclusion criteria: children with: other neurological disorders; nonepileptic attack disorder; global mental retardation	Focus groups with children. Grounded theory analysis.	Two major themes were identified relating to 'growing up' and to 'epilepsy'. Each had a number of subthemes highlighting the challenges and the issues children described. There were no significant differences between the age groups.
Mu, 2008	Taiwan	To investigate the essence of the family health-illness transition experience from the parental perspective when a child is afflicted with epilepsy	N = 18 (10 couples, 2 fathers not participating) 10 female, 8 male Age of cwe: 3–7 years Duration of epilepsy: 18 months Medication: no information given Seizure type: no information given Seizure frequency: no information given Exclusions: no moderate to serious learning disabilities	Interviews with parents (couples). Phenomenological analysis.	The data were organized into 3 themes – psychological reactions, coping patterns, and family resources. The parents' psychological reaction was that of being emotionally traumatized and physically exhausted. Parental coping patterns involved parents being vigilant reframing the parental role. Parents reported the stigma associated with epilepsy and the social challenges that arose as a result. Family resilience was an important resource in coping with epilepsy.
Nguyen, 2015	Australia	To investigate parental narratives and experiences in the aftermath of an epilepsy diagnosis	N = 21 21 female Age of cwe: 1–15 years Duration of epilepsy: 6 months–5 years Medication: no information given Seizure type: absence (5); tonic-clonic (4); myoclonic (1); simple partial (2); complex partial (4); mixed (5) Seizure frequency: no information given Exclusions: diagnosis longer than 5 years	Semistructured interviews with parents. Thematic analysis.	The analysis revealed common effective cognitive appraisals that include maintaining a positive outlook, restructuring expectations, and finding meaning from their experiences. Problem-solving, emotional venting, time to self, and speaking with parents in similar situations were behaviors that buffered against carer strain. The coping strategies identified in this study can be seen as sources of resilience and therefore provide a guide for improving parent outcomes in the context of pediatric illness.
Poyner Reed, 2013 (PhD thesis)	USA	To describe the parental perspective of caring for a child with intractable epilepsy	N = 12 parents (of 7 children) 7 female, 5 male Age of cwe: 7–12 years Duration of epilepsy: 2–7 years Medication: no information given other than that the epilepsy was intractable Seizure type: no information given Seizure frequency: no information given Exclusions: (1) a non-English speaking parental caregiver and (2) a parent who lived outside a 100-mile radius of Boston, unless the subject consented for the interview to be conducted at the hospital	Interviews with parents. Thematic analysis.	Themes that emerged were the following: challenges on the journey to diagnosis; difficulties in medication management; negotiating and advocacy for education; health care provider challenges; communication and partnering; and the important role played by siblings, other family members, and friends.
Roberts, 2011	Canada	To improve understanding of the school experiences of children with epilepsy; to identify the perceptions and experiences of the primary caregivers of young children	N = 7 caregivers Gender of parents: no information given Age of cwe: 5–11 years Duration of epilepsy: 1–6 years Medication: all but one on at least 1 AED. Seizure type: complex partial (2), grand mal (2) absence (2); petit mal (1)	Interviews with parents. Thematic analysis.	Five categories were elicited from the families' narratives: health-related issues, family coping, academic experience, social belonging, and awareness.

		with epilepsy regarding their interaction with schools which impact on the family and the child's quality of life; to clarify how schools can best support, accommodate and prepare for these children and their families	Seizure frequency: no information given Exclusions: no information given		
Ronen, 1999	Canada	To identify key aspects of health-related quality of life (HRQoL) for children with epilepsy to better inform HRQoL instruments	N = 29 (children); 42 (parents) 18 female, 11 male (children) 28 female, 14 male (parents) Age of child: 6–10 years Duration of epilepsy: 6 months–9 years (mean = 18.4 months) Medication: all on at least 1 AED. Seizure type: partial (10), generalized tonic–clonic (4); absence (7) absence and GTC (2); partial and GTC (5); myoclonic and absence (1) Seizure frequency: all had active epilepsy defined as more than 2 unprovoked seizures in the preceding 24 months. Exclusions: major morbidity other than epilepsy including autism, profound mental retardation, cerebral palsy; children who were easily distracted from process; and children who did not attend school regularly	Focus groups with children. Focus groups with parents. Textual thematic analysis.	Five dimensions of health-related quality of life were identified – the experience of epilepsy, life fulfillment and time use, social issues, impact of epilepsy, and attribution.
Rushe, 2011 (D. Clin Psych thesis)	UK	To explore and examine the experiential views of eight children (10–14 years) who have siblings with a prior diagnosis of refractory epilepsy	N = 8 siblings 4 female, 4 male Age of sibling: 10–14 years Duration of epilepsy: 1–13 years Medication: all the cwe were taking between 2 and 4 AEDs. Seizure type: idiopathic and symptomatic epilepsy, diurnal and nocturnal seizures. All seizures were refractory to medication. Seizure frequency: daily (5); weekly (1); monthly (2) Exclusions: siblings of children with epilepsy on the ketogenic diet or attending the service for less than 6 months	Interviews with siblings. Interpretive. Phenomenological Analysis.	Three common themes emerged from the analysis: <i>Encountering epilepsy</i> , siblings' initial and ongoing relationship with epilepsy; <i>Emotional impact on self</i> , feelings associated with grief, loss and change in a sibling, concern for parents, and acceptance; and <i>Growing up with epilepsy</i> , indicated that siblings review the ongoing and future impact of the condition.
Smith, 2014	USA	To explore caregivers' perceptions of the caregiving process at different time periods postepilepsy diagnosis	N = 19 16 female; 3 male Age of cwe = 1–17 years Duration of epilepsy: less than 12 months–more than 5 years. Medication: all were on at least 1 AED Seizure type: no information on seizure type. Thirteen had intractable epilepsy and seizures were controlled in 6 cwe. Seizure frequency: no information given Exclusions: caregivers of a child with epilepsy with a diagnosis of a comorbid or life threatening medical condition	Focus groups with parents. Thematic analysis.	The prevalent theme that emerged during the data analysis was navigating the noncontingencies (lack of a perceived relationship between action and outcome, unpredictability). This was supported by the subthemes, namely, blessings and sacrifices, uncertainty today and tomorrow, constant vigilance, and caregiving is more than parenting. The focus groups displayed similarities and differences in caregiving perceptions across the three postdiagnosis time periods, providing support for conceptualization of the caregiving as a multifactorial, multidirectional, and fluid process.
Wagner, 2009	USA	To provide an in depth examination of the impact of pediatric epilepsy on youth (per caregiver report) in an economically disadvantaged state within the USA	N = 7 No information on study participants' gender Age of cwe = 1–21 years Duration of epilepsy: no information given Medication: 5 were on at least 1 AED, 1 was not on medication, no information for 1 Seizure type: no information given Seizure frequency: within last month (3); within last year (2); none within last year (2) Exclusions: no information given	Focus groups with parents. Thematic analysis.	Analysis revealed 3 themes: caregiver reports of medical concerns including medication management and interaction with schools in relation to medication and seizure response; educational concerns including lack of knowledge about epilepsy within schools and the burden of advocacy falling on parents; and social concerns reflecting caregivers' concerns about the social isolation of their child and siblings.

responsibilities. Several studies highlighted the time of diagnosis as being particularly challenging for parents in relation to their lack of knowledge [30–32], but parents also raised issues relating to the ongoing management of their child's condition: knowing when their child is having a seizure [29]; what to do when they have a seizure [27]; and when to take their child into the emergency department [31]. Siblings reported difficulty in understanding epilepsy [34] but said that having information reduced their anxiety [21].

3.2.3.2. Prevention of seizures. Taking medication played a key role for cwe in preventing seizures. Many studies reported children being aware of the benefits of medication despite their concerns about the side effects and social implications as noted above [17,18,24,28]. However, some reported difficulties remembering to take medication [26] and of their parents forgetting to give them it [28] and a frustration when the medication did not prevent a seizure [20]. There were also other forms of prevention mentioned by cwe including body management, for example, maintaining regular sleep patterns [18]; limiting any trigger activities [17,26]; and being aware of auras [22]. Nevertheless, some cwe reported the need to be constantly in control as challenging to maintain [18,20] and reported that experimenting by not adhering to an optimal regime (medication and lifestyle) helped them not only to feel more normal but also to identify what risks they felt they could or could not take [18]. While parents also emphasized the importance of medication, they also expressed frustration at the lack of control over seizures [30,35].

3.2.3.3. Managing social relations. Children with epilepsy described ways in which they dealt with the potential and felt the impact having epilepsy could have on their peer relationships. Primarily, such management revolved around the issue of disclosure. Several studies reported cwe not disclosing their epilepsy to peers [16,17,24–26,28], for example, going to the toilet at school to take medication to ensure that it was not seen by others [26]. Nondisclosure was therefore a means by which they could maintain their 'normality', and the lack of visibility of epilepsy (other than during seizures) made this an option for cwe [16]. However, some cwe also expressed concerns that they may be less safe if they had a seizure and their friends did not know what was happening [26]. In addition, some emphasized the need to educate peers about epilepsy in order to address any issues around exclusion or bullying [16,19,22]. Parents' accounts were similar to the children's highlighting the balance between wanting their child to be considered 'normal' while ensuring that their safety was central to the issue of disclosure [29,30], although in some educational contexts, disclosure to the staff was mandatory [32]. Siblings reported that telling others about epilepsy was challenging because they worried about reactions and, in particular, the impact that stigma associated with epilepsy would have for them and their sibling (cwe) [34].

3.2.3.4. Support. Children with epilepsy emphasized the importance of support from their parents and siblings [17,18,28]. Despite the challenges with peer relationships, friends were also highlighted as providing important emotional and, in times of seizures, practical support [19,22,24,28]. Support from health care professionals was not always addressed in the studies with cwe. In those that did ask cwe about this, a mixed picture emerged. While relationships were reported positively [20], particularly with epilepsy nurses [18], cwe also noted that it was difficult discussing sensitive topics, for example, relating to sex [26] and that doctors talked over them in language that they could not always understand [27]. Parents emphasized not only the value of support from siblings [31] and from extended family [29] but also the need for more support and practical advice from health care professionals [23,27]. However, seeking professional help was also reported as being difficult for some parents. Jones et al. highlighted that parents conceptualized their child's condition in different ways and that the

way parents thought about epilepsy influenced their expectations of and response to clinicians' advice [23].

3.2.3.5. Concerns and hopes for the future. The findings from studies that reported the concerns and hopes of cwe about the future presented a mixed picture. There was hope expressed by some that their epilepsy would disappear [24,26,28], but if it remained, some said that they would not let it affect their life choices [24]. Other cwe were more circumspect about potential limitations expressing concerns that their career options may be more limited [26,28] and that having children may be more difficult [26]. Parents' concerns related not only to their child's future but for them meeting the developmental and social milestones considered 'normal' for each age. However, the extended caregiving role, noted above, was also reported as having future implications in challenging the normal trajectory towards independence from the parent as the child becomes an adult, as well as also creating uncertainty as to whether the child will be able to care for the parents in their older age [35].

3.3. Research involving children with epilepsy and their families

This section describes the research methodology and methods of the studies. Applying the appraisal criteria (see Table 3), the quality of reporting and appropriateness of methods adopted are presented in relation to research design, data collection, data analysis, and ethical issues.

3.3.1. Research design

The aims of the studies and the contexts within which they were being undertaken were all clearly identified. Sample size varied considerably: from 4 to 49 (mean = 22.5) in the studies including only cwe/siblings; from 7 to 22 (mean = 17.7) in studies including only parents; and from 7 to 71 (mean = 23.8) in the studies involving parents and cwe/siblings. The recruitment of only children, only parents, or both was justified in relation to addressing the stated aims of the studies, and there were no instances where children's experiences were accessed via parents. Section 3.1 highlighted that detailed information on the sample was not consistently presented, with frequent gaps around key sociodemographic characteristics and epilepsy type. Further, there was some confusion around terminology and measures applied in relation to discussing duration of epilepsy and frequency of seizures.

Some studies reported the process by which the interviews were designed, but most did not provide this information. Six developed the interview topic guides with input from clinicians and other relevant experts, including qualitative researchers [17,18,20,22,27]. One study with caregivers mentioned including people with epilepsy to inform the design process [36]. No studies reported involving children or young people in the research design.

3.3.2. Data collection

The majority of studies used semistructured individual interviews with children and individual or paired/couple interviews with parents. Four studies used focus group interviews with children [26–28,33], and three studies used focus groups with parents [27,33,35]. Of the studies involving children as participants, seven discussed the development of specific methods taking into account the age of the participants. This included attempts to make the atmosphere conversational [20] and to develop a rapport [16]; the inclusion of props, for example, a puppet to help children to feel more at ease and to encourage communication [19], and a range of activities in the interview to facilitate discussion of the topics [16,24,27,28,33].

3.3.3. Data analysis

The predominant form of qualitative data analysis used in the studies was thematic analysis. Reporting on the process of data analysis

varied considerably with some providing detailed accounts of the stages involved [18,19,23,28], while others gave very little information. None of the studies raised any specific issues in relation to the analysis of data from children. Several studies noted the steps undertaken to ensure reliability and validity in the analytic process. The reliability of analysis was enhanced by including several members of the team independently attributing themes to the data [19,21,23,25–28,30,35]. To enhance validity, several studies included participants in rechecking the interpretation that had been given to data [19,26–28,30,32,35].

3.3.4. Ethical issues

Processes relating to ensuring that ethical principles were applied were presented in most articles, though there was limited discussion of the specific challenges when involving children and young people in research, including consent, the relationship between researcher and participants, and confidentiality. Six of the studies reported seeking informed consent from the children and young people [17–19,24,26,28], and five reported seeking assent [16,22,25,27,34]. In one study, the involvement of the child (sibling) in giving consent was not clear as it stated that ‘families’ agreed to take part [21]. Five studies made no mention of having sought and gained approval from a relevant ethics committee [20,24,30,32,33]. Only one study reported how the issues relating to confidentiality in research with children and young people were addressed [34].

In some studies, the authors were involved in both the research and the clinical care of the children who were participating [18–20], but only Elliot et al. discussed the implications of this for ethical processes [19]. The authors reported advantages of the child knowing the researcher, both in terms of rapport and the researcher being familiar with their case, while also noting that being in an established relationship can present challenges to consent processes. However, the authors did not say what these challenges were or how they addressed them.

4. Discussion

This review synthesized qualitative research with cwe, parents, and siblings and presented an analysis of the studies’ key findings and issues arising in relation to research methods. In the following section, the implications of this for future research and practice are considered.

4.1. Key research themes: normalcy and agency of children

Living with epilepsy has an impact on many aspects of a child’s life including physical and mental health, educational achievement, and social relations. Cutting across many of these issues, the challenge of experiencing what is perceived to be a ‘normal’ childhood emerged as a dominant theme across the studies. First, normalization may involve ‘keeping up’ a normal lifestyle [37] either by seeking to maintain previous everyday practices in the face of change brought about by an illness or by ‘keeping up’ with peers. There was little within the studies that gave a before/after picture of change arising from the onset of epilepsy among the children, so there was little mention of this form of normalization. This may have been because of the focus on the research on the present ‘impact’ of epilepsy on their lives rather than a biographical approach that may not only explore change in more detail but may also reflect the fact that many children would remember little of their life before epilepsy, given the young age of onset for many. Rather, normalization (for both cwe and parents) involves drawing on the experiences of peers and on discourses of a ‘normal’ childhood, adolescence, and adulthood to assess cwe’s experiences and anticipated futures. Second, normalization in the context of illness is also sought by ‘passing’ or ‘covering’ (attempting to conceal a condition to ‘pass’ as ‘normal’ or reducing its significance by containing its noticeability) [38]. Evidence from the studies included in this review indicates that some cwe limit disclosure of epilepsy to others in order to ‘pass’ as normal and minimize the impact it may have – ‘covering’ – to avoid the potential

negative implications of such difference including the stigma associated with epilepsy. In the studies with parents, the impact of epilepsy on their parental caregiving role and identity was noted, but the extent to which parents engaged in different forms of normalization – ‘keeping up’, ‘passing’, or ‘covering’ – has not been fully addressed.

Normalization may be central to many of the studies’ findings because the desire for children to belong, and the parental hope for their child’s life to be the best it can be, is fundamental to experiences of childhood and parenthood. That normalization is so rooted in those experiences presents challenges to finding ways to address any negative implications that may arise. At the individual level, clinicians can work with cwe, for example, to build their self-esteem. However, normalcy, while experienced individually by children and their families, is very much a relational term, and work is also required at a broader social level, though partnership between clinicians, schools, epilepsy support organizations, and families, to improve awareness and knowledge about epilepsy and so to reduce any stigma.

A second key theme that emerged across the studies was the agency of children in reflecting on and coping with epilepsy. The studies highlighted that children have knowledge about their own condition and epilepsy more generally and that they are involved in managing the ways in which they cope with epilepsy, both in terms of seizure prevention and managing their relations with others, particularly peers. This is reinforced by research with children in many areas, including related to their health, which illustrates children’s agency in both understanding and being actively involved in shaping their lives [39–41]. However, within the epilepsy literature, there has been limited attention given to children’s involvement in their own care, both in formal health care contexts and within the family. This perspective is needed to enable a fuller understanding of the facilitators and barriers to children’s participation as partners in their health care [42]. Specifically, the experiences and implications of the triadic health care relationship [43] involving child, parent, and health care professionals in epilepsy care have not been considered from either children’s or parents’ perspectives.

4.2. Research involving children and families

This review demonstrates that researchers are seeking children’s experiences directly from children rather than by parental proxy. While the intention to focus on children’s accounts gives potential validity to research exploring their experiences, the rationale for selection of the methods adopted and the attention given to the design of appropriate research tools were mixed. There is a vast body of methodological literature within childhood studies that could be better utilized by those involved in designing and conducting research with children and families (for example, [44–46]). Moreover, increasing attention is being given to children’s participation in all stages of the research: advising on design, as interviewees but also interviewers; contributing to data analysis; and dissemination [47]. Such participation could be considered when designing research with cwe.

The involvement of children in research also clearly has an ethical dimension, although the discussion of this within the studies was limited. Not all studies were clear on why assent rather than consent was sought. Questions have been raised regarding whether children can completely understand a research study and their role within it in order to provide fully informed consent [48]. With these concerns in mind, some researchers seek assent, a proxy consenting procedure where a parent or guardian provides informed consent for participation on behalf of a child, fulfilling the ‘legal’ informed consent procedure, with the child then verbally agreeing/assenting to take part [48,49]. However, such a process may be disempowering and fail to adequately take account of the children’s capabilities and levels of understanding. The onus is on the research team to ensure that the research study information is presented in an easy-to-understand and age-appropriate manner in order to facilitate children to provide informed consent. There was

also limited discussion, within the studies examined, on how this initial consent/assent was sought from children, with few discussing the way consent was checked throughout the research. Seeking consent in research with children should be an on-going process [50], and there is a range of methods adopted to achieve this [51]. Furthermore, the need to adopt easy opt-out mechanisms is particularly significant in contexts where the research is conducted by the child's clinical team, creating the potential for the child to feel pressure to agree to participate [19].

Information on participants' sociodemographic status was given in most studies although few presented information on socioeconomic status or ethnicity. The studies also included information on the range of types of epilepsy and status and included those whose epilepsy was well/less well controlled. However, the use of different terminology in categorizing and describing the participants' epilepsy profiles makes it more difficult to compare findings across studies. Moreover, while some comparisons were made between different age groups, despite having a heterogeneous age sample, many studies did not compare between different groups of children. In moving research forward, a more nuanced approach investigating similarities and differences between groups of children would add to the understanding of children's experiences and may provide knowledge with further potential to personalize care practices; research could compare experiences of different epilepsy profiles, for example, those with controlled/uncontrolled epilepsy or different epilepsy types. It may also be useful to compare between families living in contrasting socioeconomic circumstances given the influence of socioeconomic status (SES) on health-related behavior and experiences of illness.

There are also some groups whose voices are somewhat neglected in the research literature. Among cwe, those with learning difficulties were often excluded from the research. While involving children with cognitive impairments presents particular methodological challenges, disability and childhood studies highlight the importance of an ethical, inclusive approach to research and provide many examples of practical guidance on research design and data collection [52]. Connected to this, many studies excluded children with comorbidities. An argument could be made that including children with comorbidities may make it more difficult to understand the specific impact of epilepsy. However, given that a significant proportion of children with epilepsy also live with other diagnosed conditions, the impact of living with comorbidities requires further attention [53].

Moreover, there are also disparities in which family members are represented in the research. Parental research has primarily focussed on mothers, as they are deemed to be the primary care provider. As a consequence, less is known about the nature and extent of fathers' views and experiences and of the way in which parental caring roles are negotiated in dual parent households and across households where biological parents are not coresident. This gap also highlights that limited attention has been given to the family or household unit [54]. In examining 'family' and the impact of pediatric epilepsy, it is important to include multiple family members' views within a study in order to build a more holistic picture of how the routine, everyday practices within families are not only experienced by individual members but also negotiated between family members in the context of epilepsy.

5. Conclusion

Qualitative research on pediatric epilepsy has provided unique insights into experiences of children with epilepsy, their parents, and siblings. It is important for future research to address the gaps in knowledge highlighted above and, in doing so, to ensure that appropriate design, data collection, and analytic strategies are adopted to facilitate the participation of all family members. Enhancing the quality of the research will, in turn, optimize validity and opportunities for the translation of findings into better health, education, and social practices to improve care for children and their families affected by epilepsy [55].

Ethical publication statement

We confirm that we have reviewed the journal's position on issues involved in ethical publication, and the work described in this paper is consistent with those guidelines.

Conflicts of interest statement

There are no known conflicts of interest associated with this publication.

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Paediatric illness and care: more than just feeling poorly

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Abstract

The medical education curriculum in the UK includes a component on understanding and appreciating the psychosocial aspects of illness and care. Yet, children's own experiences of illness and care are often overlooked. This article explores these neglected experiences and insights through an examination of paediatric epilepsy. The psychosocial implications of being diagnosed and living with epilepsy for children and their families are wide ranging, affecting physical and emotional wellbeing and involvement in everyday activities as well as being burdensome to manage and treat. As such, children and their families have to utilize various coping strategies in order to incorporate epilepsy into their lives. Obtaining and appreciating children's own experiences and perspectives can highlight key challenges for healthcare professionals working with these patients and their families, including recognizing children's autonomy, effective communication with them, and acknowledging the wider context of children's lives.

INTRODUCTION

Illness and care do not occur in isolation – both are influenced by a range of social and psychological factors. Understanding these dimensions of illness and care is a core proponent of medical education in the UK.¹ This is reflected in the design of the medical curriculum, which expressly aims to ensure that graduates have the skills to identify and understand the impact of societal and behavioural factors that contribute to illness or can impede treatment success.^{1,2} Despite this laudable aim, there is often not enough time or space given to allow students an in-depth exploration of these influential factors.³ In particular, children's own experiences of illness and care are not often represented in the curriculum.

This neglect is also sadly reflected in wider social science and clinical research.⁴ Research has previously focused on *parental* reports of children's illnesses, using these as the lens through which to explore the impact illness has had on their child's life.⁵ Although this perspective has value, recent literature in this area has suggested that obtaining children's own experiences and accounts of illness and care provides much richer insights.⁶ This acknowledgement of the value of seeking children's perspectives directly reflects a broader shift in our recognition of children's ability to understand and articulate their experiences and their right to be heard.⁷ This shift has primarily been driven by the introduction of the United Nations Conventions on the Rights of the Child⁸ and, more recently, the increasing focus on the child directly as the primary service user in the field of paediatrics.



This article aims to build upon this by exploring how children experience illness and its associated psychosocial impacts, focusing specifically on paediatric epilepsy, a chronic condition that is often diagnosed in childhood. Epilepsy is a complex condition that is considered a spectrum disorder, and carries with it a high risk of comorbidities.⁹ Consequently, a diagnosis of epilepsy holds a variety of implications for a child's life beyond the physical effects associated with seizures.¹⁰ The primary goal in contemporary epilepsy management and treatment is therefore to optimize the child's life in order to give them a lifestyle that is as free as possible from not only the medical but also the psychosocial effects of their condition.¹¹ This makes it an ideal example through which to explore the broader topic of children's experience of illness.

This article begins with a brief exploration of the similarities and differences between child and adult patients in terms of psychosocial implications of illness and care. This is followed by an examination of the psychosocial impacts of epilepsy on children, before moving on to explore children's own accounts of coping with illness, including the role their immediate family has within the coping process. In the final section, a discussion of the challenges facing medical professionals as they engage with children in a healthcare context will be presented.

Children and adults: different?

Illness can have different clinical presentations in children and adults, and both groups will also respond differently to treatment. Similarly, the psychosocial impacts of illness will influence them in differing manners. Childhood and adolescence are stages of life characterized by rapid and extensive physical, social, emotional, and cognitive development.¹² How children experience illness is inevitably shaped by their stage in life, the degree to which they are able to understand and/or accept their illness and associated care, their interactions with adults, the meaning of illness in their lives, and what they prioritize as significant and

important.^{4,7} Put simply, the differences between children and adults developmentally will shape the psychosocial impact of illness and care. It is important to understand these differences and the resulting challenges when providing care for young patients.

Psychosocial impacts of illness: children with epilepsy

Research has identified that epilepsy can have a significant physical, emotional, and social impact on children's lives. It is also not uncommon for other neurological (e.g. autistic spectrum disorder) and non-neurological problems (e.g. gastroesophageal reflux) to coexist with epilepsy.^{12,13}

Physical and emotional impact

Repeated seizures can have a direct impact on children's health and wellbeing including physical injuries, muscular pains, headaches, tiredness and general lack of energy, and the need for more sleep than normal.^{14,15} The side effects of antiepileptic medication can also have ramifications for children. These can be physical – such as weight gain, stomach aches, and headaches – and emotional, such as mood changes.^{6,17}

Unlike many adults, children may not be able to fully articulate or realize the true nature of these physical and emotional changes to their bodies. For example, children have reported that antiepileptic medication can make them “feel bad” in a general sense.^{6, 16} Healthcare professionals must therefore be alert to this and understand that “feeling bad” is a justifiable side effect of epilepsy and may allude to other underlying issues. Although these physical and physiological implications of having epilepsy cannot always be entirely reduced or mitigated, an understanding of how they affect children's lives is vital to helping them live as freely as possible from the effects of their condition. This also provides an opportunity to help children better understand their condition by helping them



explore why they “feel bad” and identify the specific causes of this feeling.

Children with epilepsy often report a range of negative emotions in relation to their condition. These include feeling troubled, sad, or occasionally depressed, and experiencing frustration or anger at issues such as having seizures, medication, and the accompanying side effects.¹⁷ Feelings of fear, including that of death, have also been reported by some children in the context of what happens to them in a seizure.¹⁸ When describing social relations, children report feeling lonely or isolated, and being embarrassed about being seen having a seizure.¹⁶ Nevertheless, children also report positive emotions relating to their epilepsy, including having a sense of pride in coping with epilepsy and feeling special.¹⁸ These emotional and mental health symptoms are often overlooked or undiagnosed, and hence go untreated.^{18,19} This is because such symptoms are primarily mistaken to be a result of seizure activity.^{19,20} Therefore, an awareness of such problems that children may be experiencing but are unable to fully articulate or understand will be useful in helping healthcare, education, and social care professionals identify and mitigate potential concerns while strengthening positive coping mechanisms.

However, paediatric epilepsy does not only affect a child’s life, it also has ramifications for their parents, siblings, and wider family networks. Parents of children with epilepsy often describe feeling burnt out and exhausted from worry, and report that the constant (perceived) need to monitor their child’s physical and mental health is draining. This can be exacerbated by the challenge of acting as their child’s advocate in healthcare and education contexts.¹⁵ Siblings have also reported feeling anxious, sad, worried, and lonely or isolated in their own right.⁶

Impact on involvement in everyday activities and social relations

Beyond the direct effects on physical and emotional wellbeing, having epilepsy can also influence children’s involvement in everyday activities. Children often report limitations in their participation in social activities and education because of their epilepsy.^{15,16} The specific activities that children and young people have expressed frustration about not being involved in changes with age. While missing sleepovers and interrupting play with friends to take medication were significant concerns for younger children,²⁰ older children were more concerned with the consequences of going to nightclubs or drinking alcohol, and whether they will be able to drive.¹⁶ These varied limitations may mean, or at least make them feel, that they are treated differently from their peers, causing them stress and anxiety.

Some restrictions on what children can do in their everyday lives come from suggestions by healthcare professionals intended to minimize risk to the child, for example taking baths alone. Parents and teachers also attempt to limit the risk of injury or harm by restricting a child’s involvement in everyday activities, for example, not allowing young children to play with friends outside.^{15,16} In addition, children have also described holding themselves back from engaging in social and everyday activities because of a lack of self-confidence.¹⁶ This can create a profound impact on children’s emerging and developing autonomy.¹⁷ Keeping epileptic children safe from harm while allowing them freedom to behave like other children is clearly a challenging balancing act. Healthcare professionals play an important role in ensuring that this balance is struck through conversations with children and their parents.

This balance is also particularly paramount as the theme of “being normal” is striking in many accounts of children’s own experiences of epilepsy. Children with epilepsy describe being “normal” as vitally



important, yet many report feeling different and that they do not belong.¹⁷ Many studies have widely documented that children with epilepsy experience difficulties in making friends and are bullied and stigmatized, hence affecting their social development.² Moreover, the need to take medication serves as a constant reminder of their differences, resulting in potential issues of non-adherence to medication regimes in later life.¹⁸

Children's differing competencies and levels of understanding may preclude them from talking about the problems they are facing or from being able to articulate that something is wrong. Being aware of these potential impacts of living with epilepsy from a child's perspective may contribute to earlier interventions and support where required. It is important, for example, to note that stress and anxiety are commonly associated with depression, and that adult problems often have antecedents in childhood. Poorer socioeconomic outcomes and early deaths in adulthood following childhood-onset epilepsy are also associated with poor mental health in childhood.^{22,23} Consequently, great care and attention should be given to identifying and addressing stress and anxiety in its early stages.

Coping with illness

Given the psychosocial impacts of illness and care, it is important to understand how children and families cope with epilepsy. This can facilitate the development of supportive interventions that will enhance acceptance of the illness and ultimately assist in the coping process.¹² In this article, "*coping*" refers to both the practical response to illness and the cognitive strategies by which individuals give meaning and come to terms with their altered situation and body.^{24,25}

The accounts of children with epilepsy have consistently emphasized the importance of emotional and practical support from their parents and siblings, such as helping them through seizures and being there

afterwards to ensure that they are feeling fine.⁶ In addition, parents support and assist children by reminding them to take their medications day and night, with the hope that it will also prevent seizures.^{15,21} Other practical coping mechanisms supported by families include strategies to prevent seizures, such as maintaining regular sleeping patterns, limiting trigger activities, and being aware of auras.^{15,21} Support from close family members can help children adapt to the changes that being diagnosed and living with epilepsy brings.^{15,26}

It is important, however, not to assume that parents and children cope with illness in the same way or that they need the same support. For example, parents emphasize the importance of learning about epilepsy as it helps them to cope with their new care-giving responsibilities.^{15,27} Healthcare professionals can easily facilitate this learning by providing suitable resources. On the other hand, more information or knowledge about epilepsy is less vital to children and, for some, may even be unwanted.¹⁵ This difference between children and parents needs to be managed delicately. Given the intertwined nature of coping, it is important to ensure that parents and siblings are able to cope effectively as this will boost the child's ability to cope themselves.¹²

As noted above, coping also has a cognitive dimension that relates to how illness is given meaning. After a diagnosis of epilepsy, children and parents can crave the "normal" life that existed before.²⁸ Although a "normal" life is potentially achievable with appropriate treatment and management of the condition, it is part of the coping process for parents in particular to mourn the "old normal" and the childhood that their children could have had.

The presence of a chronic illness creates a new sense of normality; children and their families generally make adaptations and compromises in their lives to accommodate it.²⁷ Roles and routines change as the



management of the condition gets absorbed into everyday family life. For example, parents often refer to the process of reframing the parental role to include more of a carer role.²⁸ Similarly, medication regimes will form part of a new routine for everyday family life.²⁹ It is important to note, however, that children are not passive in this process; they actively participate in creating this new “normal” as they accommodate the condition and should be supported in doing so.⁷ For example, many children with epilepsy choose not to disclose their diagnosis to peers and friends to maintain their “normality”.¹⁶ Appreciating these wider impacts of epilepsy allows for a better appreciation of how children and their families begin to understand and cope with the condition now being part of their lives.

Challenges of paediatric care

Differing capabilities, life experiences, maturity levels, and the wider context of family can all prove challenging for healthcare professionals as they seek to treat and manage childhood illness.

Recognizing children’s agency and autonomy

A great deal of medical research and clinical practice on childhood illness has operated on the basis that children under the age of 12 years are not seen as capable of taking on responsibilities of or being actively involved in their own chronic illness.^{30,31} It is only at the point of adolescence that children, or young people, are seen as being able to begin taking charge of their own care.³² It is unsurprising then that decisions around participation and agency are usually mitigated by the child’s chronological age and maturity.³³

However, children have shown the capacity for a strong practical understanding of their condition. They see themselves as key contributors to their own care and appreciate adults engaging with them in ways that acknowledge this.³² Alderson and colleagues³² demonstrated that from as young as 4 years of age, children start to understand the principles of the diagnosis of diabetes and make responsible decisions

regarding management. Their competence to consent was developed through their experience rather than age. Furthermore, children demonstrated and enacted their agency – as social agents making choices and taking responsibilities in conjunction with those around them.^{4,33} It is therefore important that children’s contributions in healthcare discussions should be recognized as valuable and reliable,³¹ and that paediatric healthcare professionals should acknowledge children’s agency and autonomy through their conversations and in the decision-making process, instead of deciding this solely based on a child’s age.

Developing effective communication

Our society is structured around a generational hierarchy that results in a power imbalance between children and adults. Inevitably, this will shape expectations of the adults (parents and healthcare professionals) and the children involved in a healthcare setting. Skilful communication is therefore required to facilitate children’s meaningful participation in their care. This includes the following: being mindful of different capacities and priorities of children, taking care not to be patronizing, describing why their views are being sought, and how this situation might be different from what happens in other contexts, for example in school. Offering children alternative ways to communicate and participate, or simply to help them feel at ease during an appointment, can also allow them to set the style of conversation engagements. How children prefer to communicate and participate may change as the child becomes more confident, and certainly as they become older, so it is useful to do periodic checks on whether the child is happy with the process and styles of communication.^{32,33}

Acknowledging wider contexts of children’s lives

As highlighted above, it is important to appreciate that children are generally not experiencing their illness alone. Parents and healthcare professionals hold key roles in a child’s life, particularly in the context of



illness.^{5,34} They are both facilitators and restrictors to a child's agency, often making decisions as to whether the child is "able" or "capable" to participate in discussions and to what extent and form this participation takes.⁵

LeFrancois³⁵ highlighted that the connection of this with age and competency is particularly acute when children actively take responsibility for their health and medication in a manner that differs from their parents' perspective. According to LeFrancois, when such views differ, parents are likely to elicit a protectionist response and deem their children as both vulnerable ("too young") and incompetent ("immature") by virtue of their status as a child with a chronic illness.³⁵ The connection of chronological age and maturity with competence, and correspondingly with agency, can lead to children appearing passive with no role to play in their own illness and care.³⁶ It is important that healthcare professionals do all they can to ensure that children are provided ample opportunities to exercise their agency through effective communication.⁵ Furthermore, parents themselves may also need more information and support, which can potentially result in them dominating the discussions. Opportunities for parents to discuss concerns with healthcare professionals independently may also be valuable, such that time spent with the children will be focused on them and their needs.

Coyne³⁴ illustrated that children's emerging autonomy needs to be fostered by both parents and medical professionals. Both have a significant influence on whether a child's efforts to participate are supported.³⁸ Being aware of interactions and ensuring that parents do not dominate or dismiss children's views and opinions is important for effective communication and, in turn, for recognizing children's autonomy.⁵

CONCLUSION

This article sought to draw attention to children's experiences of illness and care using the example of

paediatric epilepsy, where the impacts of the condition are wide ranging and entrenched. Although the issues discussed specifically pertain to epilepsy, similar connections can be drawn with other chronic paediatric conditions such as diabetes and asthma.^{5,37,38} However, children with epilepsy can, to an extent, "hide" their epilepsy from friends to maintain their "normality" to others; this is not possible with conditions such as asthma where disclosure is inevitable. There are similarities in response to diagnosis for children and parents, but there are also differences.

Children do not experience illness and its care alone; parents also experience ramifications and manage their children's psychosocial needs as well as their own in the process, as both move towards a new family life that incorporates it. Having an awareness of how a diagnosis can be perceived by the child, family, and wider social circles will ensure that children with epilepsy and their families can be fully supported by healthcare professionals throughout the course of the illness and its treatment. Key challenges to working with paediatric populations highlight the need to recognize children's autonomy and agency, to engage in effective communication, and to understand their wider contexts of family life.

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