

The Experience and Management of Childhood Epilepsy within the Family

THESIS

PRESENTED FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

BY

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Declaration of Authorship

I Michelle Webster hereby declare that this thesis and the work presented in it is entirely my own. Where I have consulted the work of others, this is always clearly stated.

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Abstract

Epilepsy is the most common chronic neurological condition in the UK; however, there is little research detailing children's experiences of living with epilepsy. More generally, only a small amount of research has explored siblings' experiences of having a brother or sister with a chronic condition. Additionally, despite increasing use of the ketogenic diet (a treatment for drug-resistant childhood epilepsy), it has not previously been researched from a sociological perspective.

The findings presented within this thesis are based on data collected from 24 families that had a child with epilepsy aged 3-13 years, who were being treated with either antiepileptic drugs or a combination of drug and dietary treatment. Data collection comprised 14 group interviews, 23 in-depth interviews with parents and autodriver photo-elicitation interviews with 10 children with epilepsy and 10 siblings. The data were collected and analysed using a constructivist grounded theory approach.

The findings are framed by the concepts of uncertainty, risk and family practices. Indeed, experiences of uncertainty were common among family members and they responded to uncertainty by living in the present, reducing uncertainty, hoping and waiting. Children and parents viewed medications differently, and the meanings attached to foodstuffs were often altered due to implementing dietary treatment. Parents prioritised minimising what they perceived to be physical risks to the child, whereas the children were most concerned about reducing the risk of being stigmatised. Additionally, changes to family practices affected family relationships and it was found that siblings contributed to care work within the family by taking on three caring roles – the alert assistant, substitute parent and parenting assistant roles. Overall, the findings presented within this thesis contribute to the sociology of health and illness and the sociology of childhood by providing a detailed insight into the experience of daily life in families with a child with epilepsy.

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List of Abbreviations

AED	Antiepileptic Drug
CT	Computerised Tomography
EEG	Electroencephalogram
ESUK	Epilepsy Sucks UK
ILAE	International League Against Epilepsy
MAD	Modified Atkins Diet
MCT	Medium Chain Triglyceride
MRI	Magnetic Resonance Imaging
SUDEP	Sudden Unexpected Death in Epilepsy

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Chapter One: Introduction

This thesis focuses on the experience and management of childhood epilepsy within the family. Epilepsy is an exceedingly complex condition and ‘no single term can adequately describe this extremely broad spectrum of clinical manifestations and possible seizure patterns encountered in clinical practice, especially in children’ (Desurkar, 2012: 131). Therefore, this introduction begins with an overview of the clinical literature on epilepsy in order to provide some background information on the condition. Attention then shifts to the focus of this study; the aims for the project are presented and the methodological approach taken is explained. Lastly, the structure of the thesis is outlined.

1.1 Epilepsy – Clinical Overview

Epilepsy during childhood is the focus of this overview. To begin, epilepsy is defined and prevalence rates and the causes of the condition are outlined. Details of the various seizure types will then be provided. Finally, a discussion of two of the possible daily treatment options for childhood epilepsy will be presented – antiepileptic drugs (AEDs) and the ketogenic diet – and emergency medications will be introduced. This overview only covers AEDs and the ketogenic diet as one of the aims of this piece of research is to compare experiences of utilising these treatments.

1.1.1 Medical Definitions, Prevalence and Causes

Epilepsy is defined as a ‘propensity to spontaneous epileptic seizures or to epileptic seizures induced by stimuli that do not induce seizures in most people’ (Alarcón, 2012a: 329); and an epileptic seizure is ‘a sensation, feeling, autonomic change, abnormal or automatic movement or alteration of consciousness associated with abnormal EEG changes’ (Alarcón, 2012b: 6). A detailed description of the different types of epileptic seizures is given in the next subsection.

Epilepsy is the most common chronic neurological condition in the UK (Chadwick, 1994; Smithson and Walker, 2012). Among children incidence rates are slowly decreasing due to less brain trauma during childbirth (Alarcón, 2012a). Despite this trend, epilepsy is most common in children and the elderly (Chadwick, 1994; Brown *et al.*, 1998; Bagshaw *et al.*, 2012a), and roughly 4 out of every 1000 school age children in the UK are affected (Ross, 2012). It has been estimated that 21% of people with the condition will have their first seizure before the age of 10 and a further 25% will have their first seizure between 10-19 years of age (Moran *et al.*, 2004). For some, however, this will not be a lifelong condition; 'benign' forms of epilepsy are age specific and seizures will remit during childhood or adolescence (Neville, 1997; Sheth, 2002).

Epilepsy can be split into symptomatic and idiopathic epilepsies. Symptomatic epilepsies are the result of a lesion in the brain, which can be caused by scarring after an injury, stroke, an infection of the brain, birth asphyxia, metabolic disorders or a tumour (Reading *et al.*, 2006; Bodi and Honavar, 2012; Smithson and Walker, 2012). However, an identifiable cause can only be found in 30% of people (Alarcón, 2012a). Where there are no known brain lesions this is referred to as idiopathic epilepsy and the condition is assumed to be genetic (Alarcón, 2012c).

A small proportion of people's seizures are brought on by certain stimuli, which are known as triggers (Cull and Goldstein, 1997; Alarcón, 2012b). For example, 2-5% of people with epilepsy in the UK have photosensitive epilepsy, which means that their seizures are triggered by flashing lights, or in some people, light reflecting on shiny roads or rippling water (Espie and Paul, 1997; Desurkar, 2012). Other recognised triggers include reading, music, intellectual activity and tiredness (Alarcón, 2012b; Desurkar, 2012). However, the majority of people's seizures are unpredictable and occur spontaneously (Baker, 1997).

1.1.2 Seizure Types

There are a variety of epileptic seizures, which are broken down into two categories – generalised and focal (Chadwick, 1994; Alarcón, 2012c). Generalised seizures involve epileptic activity in both hemispheres i.e. the whole brain, whereas focal seizures are located in one hemisphere of the brain (Chadwick, 1994; Cull and Goldstein, 1997; Alarcón, 2012c). Focal and generalised seizures take a number of forms and are described in Table 1.1. The table is based on the 1981 International League Against Epilepsy (ILAE) classification, which is still used in practice today (Alarcón, 2012c). Information on the classification of seizures and their symptoms has been derived from Alarcón (2012c), Ferrie and Walker (2012) and Perkin (2005).

Table 1.1 Types of Epileptic Seizures

Seizure Type	Description
I Generalised seizures	
Absence seizures	Activity ceases, the person stares blankly and is unresponsive. Occasionally people may flutter their eyelids or their head may drop. This type of seizure may last up to 20 seconds.
Tonic-clonic seizures	Begins with a tonic phase where the muscles contract so the person becomes stiff; if standing they fall to the floor. Contraction of the diaphragm results in a gasp. The person stops breathing and may become cyanosed (skin appears blue due to lack of oxygen). The clonic phase then begins, which involves symmetrical jerking movements in the limbs as the muscles contract and relax. The jerking movements become less regular until all movements cease; at this stage incontinence may occur (urinary, faecal or both).
Clonic seizures	Clonic phase of a tonic-clonic seizure (symmetrical jerking movements of the limbs).
Tonic seizures	Tonic phase of a tonic-clonic seizure (muscles contract making the body stiff).
Atonic seizures	Sudden loss of muscle tone; if standing or sitting the person will fall to the floor.
Myoclonic seizures	Sudden jerking movements usually involving the arms or head; arms usually jerk upwards, whereas the head usually drops downwards.
II Focal seizures (without	

impairment of consciousness) with:	
Motor symptoms	Primary motor cortex: clonic movements on one side of the body or tonic posturing (extension of the arm). Movements may proceed in a 'Jacksonian march' where the movement travels through sequential body parts on one side, e.g. hand, forearm, arm, face. Prefrontal cortex: The head turns to one side or cycling or stepping motions with the legs. Speech areas: loss of ability to articulate thoughts or comprehend written or spoken language.
Sensory symptoms	Somatosensory cortex: tingling, numbness, pain or a burning sensation. Visual cortex: seeing flashing lights or shapes such as circles or ovals. Auditory cortex: hearing sounds, melodies or sentences. Olfactory or gustatory cortex: perceiving smells or tastes, usually a burnt smell or metallic taste. Insula and parietal lobe: dizziness.
Autonomic symptoms	Epigastric sensation (sinking feeling in the stomach), paleness, flushing, sweating, dilatation of the pupils, piloerection (goose bumps), change in heart rate, change in respiratory rate, erection, urination or defecation.
Psychic symptoms	Memory disturbances: flashbacks, déjà vu (new experience feels familiar) or jamais vu (familiar experience feels unfamiliar). Affective symptoms: extreme pleasure or pain, fear, depression, terror or anger. Cognitive disturbances: distortion of time, sensations of detachment, depersonalisation or unreality. Illusions: distortions of object size, distance, sound or altered perception of size or weight of a limb. Structured hallucinations: hearing music or scenes that are not real.
Focal seizures (with impairment of consciousness)	Person will be only partially responsive or completely unresponsive. The person may stare or appear distant. The person may display one of two types of 'automatism' (normal but purposeless movements): De novo automatisms: actions appearing with the seizure, such as chewing, swallowing, lip smacking, running, walking, cycling

	movements, clapping or fidgeting. Perseverative automatisms: continuation of activity prior to loss of consciousness, such as walking, turning pages in a book or eating.
III Secondly generalised seizures	This term is used to describe a seizure that begins as a focal seizure but the seizure activity spreads to both halves of the brain resulting in a generalised seizure, which usually takes the form of a tonic-clonic seizure.

1.1.3 Diagnosis and Prognosis

The diagnosis of epilepsy can be problematic as there are no definitive diagnostic tests and it is ‘complicated by the fact that many key symptoms and signs of epilepsy are intermittent and brief’ (Alarcón, 2012b: 6). The main diagnostic evidence used by physicians is a description of the person’s seizures (Neville, 1997; Alarcón, 2012b; Bagshaw *et al.*, 2012b). Diagnosis in children is even more problematic as they may not be able to describe their seizures and because non-epileptic paroxysmal events (seizures that are not caused by abnormal electrical discharges in the brain) are more common during infancy and childhood (Bagshaw *et al.*, 2012b).

Tests are carried out in order to provide support for the diagnosis, determine the type of epilepsy and/or identify a cause. Each individual diagnosed with epilepsy will have an electroencephalogram (EEG), which is ‘a record of cerebral electrical activity measured via electrodes’ (Cull and Goldstein, 1997: 12). Individuals may also have a magnetic resonance imaging (MRI) scan or a computerised tomography (CT) scan to identify any structural abnormalities or lesions on the brain (Cull and Goldstein, 1997; Bagshaw *et al.*, 2012b).

Epilepsy is frequently over-diagnosed (Brown *et al.*, 1998) and Chadwick and Smith (2002) reported that out of 214 children diagnosed with epilepsy by one consultant in the UK, it was later determined that over a third were in fact not thought to have the condition. However, under-

diagnosis is also a problem; up to 30% of people with epilepsy are originally diagnosed with a different condition (Bagshaw *et al.*, 2012b).

It is difficult to specify a prognosis for epilepsy as the condition varies so greatly. On the whole, in the UK:

About one-third of cases have less than one seizure a year, one-third have between one and 12 seizures per year, and the remainder have more than one seizure per month (20% of these have more than one seizure per week). (Brown *et al.*, 1998: 436)

Furthermore, people with epilepsy may experience additional cognitive, behavioural and emotional problems. For example, memory problems are the most frequently reported cognitive problem in people with epilepsy in the UK (Thompson, 1997). Additionally, 60% have other disabilities, 25% of children have special educational needs and 20% have moderate or severe learning difficulties (Brown *et al.*, 1998; Ross, 2012). People with epilepsy can also incur injuries as a result of their seizures (Chadwick, 1994). Ficker found that 30% of people with epilepsy reported injuries such as 'fractures, lacerations, bruises, and burns' (2000: S7). Additionally, although accidental death is rare, it may also be a consequence of seizures (Ficker, 2000).

Sudden unexpected death in epilepsy (SUDEP) is also a concern for people with epilepsy. 'SUDEP can be defined in simple terms as the sudden death of a person with epilepsy without reasonable anatomic or toxicological explanation' (Ficker, 2000: S8). The incidence of SUDEP is estimated to be 0.27 cases per 1,000 person years for those under the age of 14 (Ficker, 2000). Although the cause of SUDEP is unknown it would appear to be seizure related, as 'it has been postulated that death results from cardiac arrhythmia or respiratory failure during or immediately after a seizure' (Bodi and Honavar, 2012: 66), with individuals experiencing tonic-clonic seizures being at greatest risk (Tomson *et al.*, 2005).

Most people will begin being treated for epilepsy when they have experienced two seizures in a short space of time (Chadwick, 1994; Alarcón, 2012b). Medications and dietary treatments for childhood epilepsy are discussed in the following subsection.

1.1.4 Treatment

There are a number of treatments for epilepsy, most of which control the symptoms of epilepsy, i.e. seizures, rather than providing a cure. The two daily treatments for epilepsy that this piece of research focuses on are AEDs and the ketogenic diet; an outline of each of these treatments is detailed below, along with a description of their possible side effects. Emergency medications are also introduced in the final subsection.

1.1.4.1 Antiepileptic Drugs (AEDs)

AEDs are the initial treatment for the majority of people newly diagnosed with epilepsy (Cull and Goldstein, 1997; Neville, 1997). The choice of which AED to use is based on the efficacy of the drug for the particular seizure type and toxicity (Chadwick, 1994). The dose of the AED can be increased to the maximum level and if this does not control the person's seizures, a second AED may be introduced (Neville, 1997). Monotherapy (one AED) is used in 68% of cases (Moran *et al.*, 2004), and is often preferred because it limits side effects and drug interactions (Ferrie *et al.*, 2012a).

There are a number of side effects that can result from the use of AEDs. Table 1.2 lists the most prescribed AEDs (those for which over 100,000 prescriptions were made between October and December 2011) (NHS, 2012) and the possible side effects they have been known to cause. The information on the side effects of each drug is derived from Stokes *et al.* (2004 cited in Ferrie *et al.*, 2012b) and Perkin (2005).

Table 1.2 Antiepileptic Drugs and their Side Effects

Drug	Brand Name	Side Effects
Gabapentin	Neurontin	Drowsiness, dizziness, fatigue, headache.
Sodium Valproate	Epilim	Hair loss, weight gain, sedation, tremor, liver damage, pancreatitis, nausea, weight loss.
Pregabalin	Lyrica	Dizziness, tiredness, weight gain.
Carbamazepine	Tegretol	Allergic skin reactions, sedation, blurred vision, dizziness, double vision, ataxia, nausea.
Lamotrigine	Lamictal	Skin rash, drowsiness, double vision, dizziness, headache, insomnia, tiredness, fever, agitation, confusion, hallucinations.
Phenytoin	Epanutin	Skin rash, sedation, drowsiness, ataxia, blurred vision, dizziness, gum hypertrophy, thickening of facial features, heavy abnormal hair growth, anaemia, slurred speech, twitching, tremor, confusion, sleep disturbances.
Levetiracetam	Keppra	Dizziness, drowsiness, irritability, insomnia, ataxia, tremor, headache, nausea, mood changes, rash, loss of body strength/weakness.
Clonazepam	Rivotril	Drowsiness and fatigue.
Topiramate	Topamax	Headache, drowsiness, dizziness, weight loss, nausea, mood change, aggression, difficulty with memory, concentration or attention.

Despite treatment with AEDs, approximately 30% of people will continue to experience seizures (Ferrie *et al.*, 2012c). Furthermore, ‘once a child fails to respond to two ... AEDs used appropriately, he or she has only a small chance of responding to further medication trials’ (Marsh *et al.*, 2006:425). A treatment that can be used for children when AEDs have been ineffective is the ketogenic diet (Farasat *et al.*, 2006).

1.1.4.2 The Ketogenic Diet

The ketogenic diet is a high fat, low carbohydrate diet that has traditionally been used to treat drug-resistant childhood epilepsy (Farasat *et al.*, 2006). It was originally introduced as a treatment for epilepsy in 1921 by Wilder in the Mayo Clinic in the United States (Marsh *et al.*, 2006; Wheless, 2008). Although it has been argued that the ketogenic diet ‘is a time-tested,

effective, and safe method for treatment of intractable childhood epilepsy' (Nordli and De Vivo, 1997: 743), its use declined with the introduction of diphenylhydantoin (phenytoin) in 1938 (Hartman and Vining, 2007; Wheless, 2008). Prior to the introduction of this AED, drug treatments for epilepsy were limited, but this new discovery shifted attention from dietary treatment to drug treatment (Ferrie *et al.*, 2012c).

However, over the past 15-20 years there has been a resurgence of interest in the diet, in both the United States and the UK (Wheless, 2008; Payne *et al.*, 2011). Between 2000 and 2007 the number of children being treated with the ketogenic diet in the UK increased by 50%, bringing the total in 2007 to 152 (Lord and Magrath, 2010). Lord and Magrath (2010) reason that the number of people using the ketogenic diet at this time was so low because the first randomised controlled trial, demonstrating the diet's efficacy, was not reported until 2008. Furthermore, numbers using the ketogenic diet may be low because it requires a high level of dietetic and neurology input to monitor efficacy and side effects in each child and specialist clinics in the UK are limited (Cross, 2012; Ferrie *et al.*, 2012c). However, recently a leading dietician claimed that the number of children receiving dietary treatment for epilepsy in March 2014 was 536 according to evidence from the caseload database for UK centres (personal communication). This figure suggests that the number of children on the diet has continued to increase since 2007.

Although the exact mechanisms of the diet are still unknown (Hartman and Vining, 2007; Neal *et al.*, 2008), it controls seizures by mimicking the metabolic effects of starvation (Nordli and De Vivo, 1997; Wheless, 2008; Payne *et al.*, 2011; Cross, 2012). This is achieved through the diet being high in fat and low in carbohydrate in order to produce ketosis (a metabolic state where the body uses ketones rather than glucose for energy) (Payne *et al.*, 2011).

Neal *et al.* (2008) carried out the first randomised controlled trial on 145 children aged 2-16 years living in the UK who had a minimum of seven seizures per week and had not responded to a minimum of two AEDs. The children were randomly assigned to two groups; the first group were immediately started on the diet (the experimental group) and the second group continued their drug treatment and began the diet three months later (the control group). After three months 38% of children in the experimental group had experienced a 50% reduction in their seizures compared to only 6% of the control group, and 7% of the experimental group had a greater than 90% seizure reduction compared to none of the control group.

It has also been noted that children may experience an improvement in cognition, alertness and behaviour whilst on the ketogenic diet (Farasat *et al.*, 2006; Hartman and Vining, 2007; Wheless, 2008). Furthermore, the positive impact of the diet appears to continue even after the diet has been discontinued; 41 children were followed up 3-6 years after discontinuing the diet and it was found that the majority had maintained or improved the level of seizure control they achieved whilst on the diet (Marsh *et al.*, 2006). Additionally, the ketogenic diet can be beneficial as, when effective, AED treatment can be reduced or discontinued (Nordli and De Vivo, 1997; Mady *et al.*, 2003; Hartman and Vining, 2007).

The ketogenic diet is, however, not without side effects. Neal *et al.* (2008) found that just under a quarter experienced side effects whilst on the diet. Side effects of the ketogenic diet include: abdominal bloating, diarrhoea, constipation (Hartman and Vining, 2007), kidney stones, thinning hair/hair loss (Mady *et al.*, 2003), reduction of bone mass and long-term cardiovascular complications (Nordli and De Vivo, 1997). Furthermore, although the diet is high in fat children may experience growth impairment (both height and weight) because the diet is calorie controlled (Hartman and Vining, 2007); however, it has been documented that growth improves once the diet is discontinued (Patel *et al.*, 2010).

The side effects listed above may cause some children to discontinue use of the ketogenic diet, but Ballaban-Gil *et al.* (2001) found that, out of 46 children placed on the ketogenic diet between 1994 and 1996, nonmedical reasons were as common as medical reasons for discontinuation of the diet. For instance, children discontinued the diet because parents felt it was too restrictive (Marsh *et al.*, 2006), or the food items were expensive or difficult to obtain (Ballaban-Gil *et al.*, 2001).

Alternatives to the ketogenic diet have also been introduced; they include the Medium Chain Triglyceride (MCT) ketogenic diet and the Modified Atkins Diet (MAD) (Payne *et al.*, 2011). Both are intended to improve palatability by increasing the flexibility of the diet and allowing a higher amount of protein and carbohydrate (Payne *et al.*, 2011). Although the MAD is not medically defined as a 'ketogenic diet', for the purposes of this thesis it will be referred to as such due to its high fat content. The ratio of fat to protein and carbohydrate on the ketogenic diet varies between 2:1 and 4:1, meaning patients receive up to 80% of their calories in the form of fat (Cross, 2012; Ferrie *et al.*, 2012c). The MAD and classical diets rely on large amounts of butter, cream and mayonnaise for their high fat content (Ferrie *et al.*, 2012c) while the MCT diet uses MCT oil and Liquigen. Other than the type of fat that each diet uses, the main difference between the diets is that protein is not limited on the MAD.

As well as daily treatments for childhood epilepsy, such as AEDs and the ketogenic diet, some children will also occasionally be treated with emergency medications, which are described below.

1.1.4.3 Emergency Medications

An emergency medication (rectal diazepam or buccal midazolam) is prescribed when someone has a history of *status epilepticus* (Walker, 2012). *Status Epilepticus* is defined as 'continuous seizure activity for 5 minutes, or two or more seizures with incomplete recovery of consciousness' (Bodi and

Honavar, 2012: 64). These medications are administered in an attempt to end the person's seizure, as prolonged seizure activity 'is associated with neurological deficits, cognitive decline and a high mortality rate' (Walker, 2012: 21). If the person's seizure continues for more than 5 minutes despite emergency medication being administered, a further dose may be administered and an ambulance should be called (Besag and Alarcón, 2012; Walker, 2012).

Now the clinical manifestations of epilepsy and possible treatment options have been outlined, attention shifts to the sociological focus of this thesis.

1.2 Focus of the Study

This study explores the experience and management of childhood epilepsy within the family. With the exception of Weinbren and Gill's (1998) work, the current sociological literature on epilepsy primarily details the experiences of adults with the condition, much of which is now dated given that it was conducted in the 1970s and early 1980s (Schneider and Conrad, 1983; Conrad, 1985; Scambler and Hopkins, 1986, 1988; Scambler, 1989; Shostak *et al.*, 2011; Shostak and Fox, 2012). Some of these authors referred to the experience of epilepsy during childhood; however these discussions are based on adults' recollections of their childhoods, rather than representing the perspectives of children themselves. As adults' recollections of their childhoods have been found to differ from children's own descriptions of their lives in the present (Hockey and James, 1993; Thorne, 1993), the information currently available regarding experiences of childhood epilepsy may not be valid from the standpoint of children. Furthermore, Weinbren and Gill's (1998) work provided only an overview of six children's narratives surrounding the condition. Consequently, this thesis represents the first comprehensive sociological study of childhood epilepsy by exploring a greater number of topics and, therefore, addresses this gap in the literature.

Treatment forms a significant part of the illness experience. Despite increasing numbers of children being treated with the ketogenic diet, how implementation of this diet affects the family and its food practices is yet to be researched from a sociological perspective. Research on those with other chronic conditions, such as diabetes, a nut allergy, coeliac disease and coronary heart disease, indicates that dietary treatments can impact on the eating practices of family members as well as the person with the condition (Kelleher, 1988; Maclean, 1991; Gregory, 2005; Pitchforth *et al.*, 2011). One aim of this study is to provide an insight into the experiences of those using the ketogenic diet and what implementing this diet meant for the meanings family members attached to foodstuffs. Parents' views on treatment in families using the ketogenic diet will be compared to the views of parents and children with epilepsy in families using AEDs in order to see how these different types of treatment were perceived.¹

Additionally, children's perceptions of medications have been largely neglected. By exploring the meanings that children attached to their medications, this piece of research will contribute to the sociology of childhood and the sociology of health and illness by detailing not only the ways in which children viewed their medications, but also how these views were related to their perceptions of the condition and what impact these views had on their adherence to their treatment regimes.

Research conducted on the impact of having a child with epilepsy on family life is also limited. There has been some research conducted in this area (West, 1976, 1979, 1990; Williams *et al.*, 2000, 2003); however, again the experiences of children are not provided as these studies focused only on parents' perspectives. As a result, a complete description of the effect that childhood epilepsy can have on family life is yet to be detailed, as the experiences of all family members have not been considered. Research on

¹ No children using the ketogenic diet were interviewed due to difficulty recruiting. This difficulty will be explained in further detail in Chapter Three.

families with children with other chronic illnesses illustrates that having a child with a chronic condition can impact on family life and family relationships. Family outings, holidays and parents' social lives have all been affected (Nocon and Booth, 1990; Bluebond-Langer, 1991; Hill and Zimmerman, 1995; Prout *et al.*, 1999; Barlow and Ellard, 2006). Differences of opinion regarding the management of conditions can cause tension in the parent-child relationship (Atkin and Ahmad, 2002) and siblings have been found to experience jealousy as a result of the attention the chronically ill child receives (Nocon and Booth, 1990; Bluebond-Langer, 1991; Stalker and Connors, 2004; Dixon-Woods *et al.*, 2005; Barlow and Ellard, 2006). It would be interesting to know whether epilepsy can have a similar impact on family life and family relationships. Drawing on Morgan's (1996) work, this study will focus on the impact of childhood epilepsy on 'family practices' and, consequently, the effect of the condition on family relationships.

Beyond contributing to knowledge on the impact of epilepsy on family relationships, this thesis will provide an in-depth discussion of siblings' experiences of having a brother or sister with epilepsy. Research on the experience of having a sibling with a chronic condition is scarce (for exceptions see Bluebond-Langer, 1991; Dixon-Woods *et al.*, 2005), and the research that is available focuses on the negative impact that having a brother or sister with a chronic condition can have. Research on those officially defined as 'young carers' has shown that children can significantly contribute to care work in the family (Aldridge and Becker, 1993; Frank, 2002; Underdown, 2002; Dearden and Becker, 2004; Warren, 2007; Aldridge, 2008; Smyth *et al.*, 2011; Wihstutz, 2011). However, little attention has been given to the care work provided by children who are not officially defined as young carers. Consequently, an aim of the research presented in this thesis is to provide a detailed account of the experiences of children who have a sibling with epilepsy, including a description of their caring roles. It is intended that this analysis will contribute to the sociology of health and illness and the sociology of childhood by expanding on the information available regarding siblings' experiences of having a brother or

sister with a chronic condition (Bluebond-Langer, 1991; Dixon-Woods *et al.*, 2005) and by providing a description of the care work that siblings take on.

Although chronic illness can impact on individuals' and their family members' lives, many people find ways to manage and limit such impacts. Much of the sociological research on epilepsy has drawn on Goffman's (1963) work on stigma, and particularly his concepts of 'passing' and 'covering'. The main management technique found to be used by adults with epilepsy, and also in families with a child with epilepsy, was concealment; this was achieved through employing the techniques of passing and covering (Schneider and Conrad, 1983; Scambler and Hopkins, 1986, 1988; Scambler, 1989; West, 1990). However, with risk consciousness now more pervasive than in the past (Giddens, 1991; Beck, 1992) and given that children tend to be seen as a particularly 'at risk' group (Jackson and Scott, 1999; Lupton, 1999; Firkins and Candlin, 2006; Meyer, 2007; Lee *et al.*, 2010), it may be that management of the condition has changed alongside this shift in the conceptualisation of childhood. This piece of research will build on the above work to determine how children with epilepsy and their parents manage the condition. Additionally, this study will assess the extent to which children and their parents use concealment as a strategy for managing childhood epilepsy in contemporary society.

1.3 Aims

Based on the above discussion, this thesis aims to detail the experience and management of childhood epilepsy within the family by exploring:

- How children with epilepsy and their parents experienced living with the condition – particularly at onset, the ongoing experience of symptoms and the way in which the condition shaped their ideas regarding the future.

- Family members' experiences of the types of uncertainty inherent in the condition and the ways in which they managed these uncertainties.
- The meanings that children with epilepsy and their parents attached to AEDs, emergency medications and the ketogenic diet. Of particular interest is whether children and their parents viewed treatments similarly or whether the meanings they attached to treatments differed.
- Parents' and children's perceptions of the risks associated with epilepsy and whether they perceived the condition to be stigmatised in contemporary society.
- The ways in which children and their parents managed these risks, alongside determining the extent to which family members used concealment to manage childhood epilepsy.
- How childhood epilepsy affected family practices and what implications this had for family relationships – particularly the sibling relationship and the parent-sibling relationship.
- The caring roles and responsibilities that siblings took on in relation to childhood epilepsy.

1.4 Methodological Approach

The aims listed above, and the research questions embedded within them, were addressed by taking a multiple-perspective approach, which incorporated gathering the views of children with epilepsy, their parents and their siblings. The findings presented within this thesis are based on data collected from 24 families that had a child with epilepsy aged 3-13 years, 14 of which were being treated with antiepileptic drugs, and the remaining 10 were receiving a combination of drug and dietary treatment.

The research was advertised through a number of UK based charities including: *Epilepsy Action*, *The Epilepsy Society*, *Epilepsy Sucks UK (ESUK)*, *Epilepsy Research UK*, *Epilepsy Parents* and two charities that support

families using the ketogenic diet – *The Daisy Garland* and *Matthew's Friends*. The charities placed adverts on their websites, online forums, social media pages, and in their newsletters.

Data collection included group interviews with all family members participating in the research in 14 of the families. In 23 of the families in-depth interviews were conducted with 27 parents (as both parents were interviewed in four families). Additionally, autodriven photo-elicitation interviews were carried out with 10 children with epilepsy (aged 5-13 years) and 10 siblings (aged 6-16 years). All interviews were audio-recorded and transcribed *verbatim*. The data were then coded using Nvivo and analysed using a constructivist grounded theory approach.

1.5 Structure of the Thesis

This thesis is divided into eight chapters. The following chapter provides a review of the sociological literature on chronic illness, the family, childhood and food, which informed the development of the research questions addressed in this study. In Chapter Three the methodological approach taken, reasons for employing such an approach and reflections on the process of conducting the research are detailed.

There are four empirical chapters in this thesis. Uncertainty was an extremely prevalent theme that ran through all family members' discussions of the condition and is, consequently, the overarching concept in Chapter Four, which is the first of the empirical chapters. Family members' experiences of living with epilepsy are outlined and uncertainties relating to the past, present and future are all covered. Additionally, the ways in which family members responded to these uncertainties are explored. In Chapter Five family members' perceptions of physical and non-physical risks associated with epilepsy are explained and the ways in which they tried to manage these risks are discussed. Next, Chapter Six focuses on the experiences of the ways in which the condition was treated; within this

chapter a discussion is presented on the meanings that were attached to medications and dietary treatments, when these meanings were similar and also when they differed. Morgan's (1996) concept of 'family practices' is utilised throughout Chapter Seven to illustrate how childhood epilepsy negatively affected family members' interactions and relationships with one another. The caring roles that siblings took on are also outlined in this chapter. To conclude, Chapter Eight provides a summary of the main findings and the contributions of this study to the wider sociological literature. Possibilities for future research are also explored within this chapter.

Chapter Two: Childhood Epilepsy Within the Family – A Review of the Literature

2.1 Introduction

This thesis focuses on how children and their family members experience childhood epilepsy, how the condition is managed within the family and how the condition and its management affect family life and family relationships. As one of the aims of this piece of research is to provide an insight into children's experiences, it is important to locate the research in the sociology of childhood. This literature review, therefore, begins with a discussion of the different ways in which children and childhood are conceptualised in contemporary Western societies because it is thought that these conceptualisations are likely to influence how the condition is managed within the family and, consequently, children's experiences of living with epilepsy.

Furthermore, as family relationships are of interest, the sociology of the family will also be drawn upon. In particular, Morgan's (1996) concept of 'family practices' will be used, as it is hoped that this framework will provide an insight into how having a child with epilepsy can impact on family life and family relationships. Thus, this concept will be introduced and an outline of the literature on family relationships will be provided. Additionally, as this study will also explore the use of the ketogenic diet, the sociology of food literature relating to food practices and meal times within the family will be detailed.

There is a lack of research detailing the experience of chronic illness from a child's standpoint; as a result, work on adults' experiences of chronic illness will be drawn upon. In particular, the concepts of uncertainty and stigma are considered in relation to epilepsy, and questions are raised regarding children's experiences of the condition. In addition, the meanings

individuals attach to medications and the ways in which people manage chronic conditions will be explored.

Finally, drawing all the literature together, the effect of having a child with a chronic illness on family practices and family relationships is outlined. Important questions are also asked regarding how having a child with epilepsy can impact on family relationships, and how epilepsy is managed within the family in contemporary society.

2.2 Conceptualisations of Children and Childhood

One of the central arguments in the sociology of childhood is that childhood is a social construct (Hockey and James, 1993; Thorne, 1993; Boyden, 1997; Prout and James, 1997; Alanen, 1998; Hutchby and Moran-Ellis, 1998; James *et al.*, 1998). Indeed, it has been argued that the concept of childhood did not even exist in Western cultures prior to the Middle Ages (Aries, 1962 cited in Jenks, 1996). Furthermore, after its development, ideas surrounding childhood have not remained consistent. Indeed, it was only during the 18th and 19th centuries that the notion that childhood was a time of innocence developed and became a dominant ideology (Hockey and James, 1993; Boyden, 1997). For example, Boyden (1997) points out that children in certain non-Western cultures take on greater responsibility, such as caring for siblings and providing economic support for their families, at a much younger age than children in the West.

The idea that children are innocent is not the only conceptualisation of children that is particular to contemporary Western cultures. It has also been noted that children are seen as both 'beings' and 'becomings' (Hockey and James, 1993; Christensen, 1998; Uprichard, 2008). They are beings in the sense that they exist in the present as social actors, and they are becomings because they are seen to be in the process of being socialised into the adults they will grow into. As a result, children occupy a dual temporal

location – they can simultaneously be viewed as both ‘people now’ and ‘people for the future’ (Mayall, 1998: 275).

However, it is argued that current societal discourse prioritises children as becomings (Christensen, 1998). This view is supported by Prout (2000) and also Hockey and James (1993) who argue that the skills children currently possess are ignored, because instead there is a focus on the skills they need to acquire in order to progress successfully into the adult domain. Furthermore, Hockey and James (1993) assert that children are not ascribed full personhood, which is set aside exclusively for adults, and as a result they are viewed as the polar opposite. Indeed, Jenks explains that:

As a consequence of the adult being regarded within theory as mature, rational and competent ... the child is viewed, in juxtaposition, as less than fully human, unfinished or incomplete. (1996: 21)

This is supported by Alderson (2007), Hutchby and Moran-Ellis (1998) and Christensen (1998) who all argue that children are seen to be incompetent in contemporary Western societies.

Furthermore, sociological theory suggests that we are living in a ‘risk society’ (Beck, 1992) where ‘risk consciousness’ is prevalent, meaning individuals use the notion of risk to organise their social worlds (Giddens, 1991). In a risk society, because children are viewed as innocent they are also seen to be a particularly vulnerable group and are, consequently, often categorised as ‘at risk’ (Jackson and Scott, 1999; Lupton, 1999; Firkins and Candlin, 2006; Meyer, 2007; Lee *et al.*, 2010). This conceptualisation of children has consequences for the way in which parenting is done. The section that follows considers family practices and family relationships, including a discussion of parenting in a risk society.

2.3 Family Practices and Family Relationships

There has been much discussion surrounding the 'decline of the family', particularly in the media and political debate, where it is argued that this decline has caused a number of social problems, especially in younger generations (Smart, 2004). However, rather than the family being in decline, it is instead argued that living arrangements are becoming more diverse and families now take a variety of forms (Finch, 2007, 2008; Chambers, 2012). Overall, the sociology of the family has moved on from looking at families from a structural standpoint to considering the relationships and interactions within them; in doing so, research on families is now more likely to reflect the ways in which individuals view their own families and family life.

Morgan (1996) was influential in this change in thinking when he introduced the term 'family practices'. Smart argues that 'this conceptual shift was a vital stage in 'freeing' the ways we think about family life and living' (2007: 33). In using the concept 'family practices' Morgan (1996, 2011) aims to convey a sense of regularity and the everyday. He also expresses a sense of the active; through family members' interactions and activities with one another they 'can ... be seen as *doing* family' (Morgan, 2011: 6 original emphasis). This view is still widely upheld and Gabb (2008) notes that families are not based purely on structural parameters but rather on relationships, and that these relationships are formed through everyday practices with others.

The following subsection details how living in a risk society has influenced family practices relating to parenting and gives an overview of what is known about the parent-child relationship. Following on from this, the sibling relationship is outlined and the literature on children who provide informal care is discussed. This section then ends with an overview of the literature on the meanings attached to foodstuffs and the use of dietary treatment within the family.

2.3.1 Parenting and the Parent-Child Relationship

As was mentioned above, within sociological theory it is argued that we are living in a 'risk society' (Beck, 1992) where risk consciousness is high, i.e. individuals use the notion of risk to organise their social worlds (Giddens, 1991). The literature on parenting suggests that risk consciousness shapes parenting practices; consequently, an overview of the relevant risk literature is presented before moving on to look at how parenting is done in a risk society.

It is acknowledged that the term 'risk' has been conceptualised in a number of different ways (Lupton, 1991; Denney, 2005). Indeed, Lupton (1999) distinguishes between three conceptualisations of risk: the 'realist' approach where risks are seen as real; the 'weak constructionist' approach where risks are seen as real but individuals' perceptions of risks are viewed as socially constructed; and the 'strong social constructionist' approach where risks themselves are seen to be socially constructed. The approach that informs the discussion of risk throughout this thesis is the 'weak constructionist' approach.

The meaning of 'risk' has also changed over time in lay consciousness. Lupton (1991) and Fox (1999) have both argued that in the past 'risk' was understood as a neutral term used to express calculable probabilities; however, in contemporary society risk is seen as being synonymous with danger, threat and hazard. Indeed, it refers to any *possible* unwanted outcome. Furthermore, Lee *et al.* argue that:

This redefinition of risk as possible danger suggests, in turn, the development of a particular view of *uncertainty* ... Rather than uncertainty being perceived as something which can be confronted rationally, or which opens up possibilities as well as pitfalls, the 'unknown' is viewed with anxiety. (2014: 11 original emphasis)

With risk consciousness now more pervasive, social actors have become increasingly 'individualised' (Beck, 1992; Beck and Beck-Gernsheim, 2002). Beck argues that in the past individuals were restricted by social structures and customs, whereas they are now more reflexive, have greater freedom over the choices they can make and, consequently, biographies are 'self-produced' (Beck, 1992: 135). However, Beck and Beck-Gernsheim (2002) note that individualisation is a double-edged sword, as although people now have more freedom, they are also deemed to be responsible for the choices they make.

Moreover, with children being conceptualised as a particularly 'at risk' group (Jackson and Scott, 1999; Lupton, 1999; Firkins and Candlin, 2006; Meyer, 2007; Lee *et al.*, 2010), individualisation has resulted in parents being seen as responsible for protecting their children from risks (Jackson and Scott, 1999; Geinger *et al.*, 2013). Indeed, 'what arises from it [the construction of the child 'at risk'] is the construction of the parent as a *manager of risks*' (Lee *et al.*, 2014: 12 original emphasis). However, Lee *et al.* (2014) draw attention to the 'double bind of parenting culture', where conflicting expert advice means all parenting techniques are viewed as potentially risky and, therefore, parents are perpetually trying to juggle competing risks.

Indeed, it has been found that parents draw on two different parenting rhetorics in their discussions of risk. One parenting discourse prioritises protecting children from risks (Jackson and Scott, 1999; Jenkins, 2006; Gabb, 2008; Hoffman, 2010; Gómez Espino, 2013), and the other centres on encouraging children to develop into competent adults by avoiding overprotection (Jackson and Scott, 1999; Backett-Milburn and Harden, 2004; Jenkins, 2006; Gómez Espino, 2013). Within the second discourse overprotection is constructed as risky and, consequently, in contrast to the first discourse, it is seen as acceptable to expose children to some risks so they learn to manage these risks for themselves.

On the other hand, drawing on the discourse that focuses on protecting children, one way in which parents try to manage risks is through what has been termed 'intensive parenting'. Hoffman argues this type of parenting is where parents 'micromanage all aspects of their children's lives in an effort to protect the child from adverse experiences' (2010: 387). Hoffman (2010) also believes this style of parenting is a direct reaction to a climate of risk. It has been argued that intensive parenting practices are largely gender specific, with predominantly mothers adjusting their family practices in accordance with this ideology (Vincent and Ball, 2007; Shirani *et al.*, 2012). Shirani *et al.* (2012) argue that men value autonomy and draw on ideas of masculinity, which consequently insulates them from the pressures of intensive parenting. Yet, there are also suggestions that constructions of fatherhood are changing and that men are now still expected to fulfil the breadwinner role whilst simultaneously being involved in their children's lives (Rason, 2001; Brannen and Nilsen, 2006). Moreover, intensive parenting has also been found to be class specific (Vincent and Ball, 2007). Vincent and Ball argue that intensive parenting specifically applies to the middle classes who view their children as 'a project – soft, malleable and able to be developed and improved' (2007: 1066). Working class parents, on the other hand, believe that their children will develop appropriately as long as they provide love, food and safety (Vincent and Ball, 2007).

Despite this comprehensive literature on parenting in contemporary society, it has been argued that children's family relationships have been given little academic attention (O'Connor *et al.*, 2004). What is known is that, in general, parent-child relationships are characterised by unequal power relations between the two parties, with parents having control over household resources and the authority to enforce discipline (Bernardes, 1997; McIntosh and Punch, 2009; Sarre, 2010). Parents decide how children spend their time – when, where and how long for – to ensure their safety and also to make sure their use of time is productive (Sarre, 2010).

The primary reason given by parents for imposing such rules is that rules act as protection from potential risks (Gabb, 2008).

Although parents impose rules they are not fixed and children often resist or negotiate with their parents (Bernardes, 1997; Mayall, 2002; Sarre, 2010). Despite these negotiations, children can only influence their parents to a certain extent; they are unable to take complete control of adult-child interactions or decisions regarding their activity participation. Indeed, Mayall (1996) and Scott *et al.* (1998) argue that although children may be in a position to bargain they can only negotiate within the limits set by adults.

As children grow older they often wish to gain independence from their parents and rules become increasingly resisted. Gabb (2008) found that adolescents went to considerable lengths to stress their desire for physical and emotional separation from their parents. Similarly, when comparing 10-12 year olds and 14-17 year olds descriptions of their lives, O'Connor *et al.* (2004) found that references to limits were only mentioned in the older children's narratives.

Given the unpredictability of seizures, and because parents mainly impose rules to protect children (Gabb, 2008), it is likely that parents of children with epilepsy will restrict their child's activities and/or independence due to the condition. However, there is limited empirical evidence detailing what rules are imposed and how they are negotiated between children and their parents. The following question can, therefore, be asked: *How do families manage childhood epilepsy?* This question will be returned to later on in the literature review when considering how individuals manage other chronic conditions. Moving on from the parent-child relationship, next the sibling relationship is considered.

2.3.2 The Sibling Relationship

Sibling relationships are complex and cannot be characterised simply as based on either conflict or friendship, as both of these are important features of sibling relationships (Kosonen, 1996; Mauthner, 2005; Punch, 2007). At times sibling relationships are caring, loving and supportive (Edwards *et al.*, 2005; Mauthner, 2005; Sarre, 2010). Some siblings enjoy having a connection with someone who knows them well and who is always there for them, as it provides them with protection from being alone (Edwards *et al.*, 2005). However, conflict is also a defining feature of the majority of sibling relationships, even for those who usually get along with one another (Edwards *et al.*, 2005).

The most common reasons for sibling conflict are disputes over sharing personal possessions, turn taking, power struggles and general irritating behaviour (Raffaelli, 1992; McGuire *et al.*, 2000). However, siblings also contradict each other or attempt to initiate conflict for no other reason than boredom (Punch, 2007, 2008). Indeed, Punch (2008) found that siblings felt they could be honest with each other about their emotions, they felt they could neglect politeness and social rules, and they did not feel the need for impression management.

It was speculated in the section on the parent-child relationship that parents of children with epilepsy may restrict the child's activities due to their condition. It is possible that this could cause tension in sibling relationships if siblings, particularly younger siblings, are allowed more freedom than the child with epilepsy. Alternatively, siblings may feel jealous if they believe their brother or sister is receiving more attention from their parents. Indeed, within the sociology of emotions it is widely asserted that emotions are in part a product of the social circumstances in which they are provoked (Hochschild, 1998; Williams and Bendelow, 1998; Barbalet, 2002). Therefore, the important question can be asked: *How does childhood epilepsy affect family relationships?* This question will also be returned to

further on in the literature review when the impact of chronic illness on family relationships is discussed more generally.

It has been noted in this subsection that an important feature of the sibling relationship is the caring aspect of this relationship. The following subsection continues with this theme, as a review of the literature on children who provide informal care within the family is presented, including a discussion on siblings who care for a brother or sister.

2.3.3 Children who Provide Informal Care

Care can be conceptualised in a number of ways. Using a broad definition, such as that put forward by Weisner and Gallimore (1977), helps to incorporate what Frank (2002) describes as the 'continuum of care' on which all children can be placed. Indeed, Weisner and Gallimore argue that children's care work can be defined as:

Activities ranging from complete and independent full-time care of a child by an older child to the performance of specific tasks for another child under the supervision of adults or other children; it includes verbal or other explicit training and direction of the child's behavior as well as simply "keeping an eye out" for younger siblings. (1977: 169)

From this definition it can be seen that children's contributions to informal care can range from providing small amounts of care to taking on high levels of caring responsibility (Frank, 2002; Morrow, 2008).

However, children's care work has been overlooked from an academic standpoint for a long time (Kosonen, 1996; Morrow, 2008). Indeed, Morrow argues that:

The fact that childhood is constructed as a period of dependency prevents us from 'knowing' about those cases of children undertaking domestic work because such work, particularly caring, is socially defined as an adult role and is a marker of adult status. (2008: 111-112)

Consequently, there is a limited amount of research into children's experiences of providing informal care.

Some researchers have looked at siblings who 'babysit' for younger brothers and sisters (Weisner and Gallimore, 1977; Kosonen, 1996; Morrow, 2008). Through their research, both Kosonen (1996) and Morrow (2008) found that the care work that siblings took on formed a significant part of the informal care provided within families. Indeed, Morrow highlights the level of responsibility that children took on when caring for a brother or sister by arguing that 'older children who babysit are symbolically and socially (but not legally) taking over the role of parent for a period of time' (2008: 114).

There is also a literature focusing on children who are officially defined as 'young carers' and take on high levels of caring responsibility (Aldridge and Becker, 1993; Frank, 2002; Underdown, 2002; Dearden and Becker, 2004; Warren, 2007; Aldridge, 2008; Smyth *et al.*, 2011; Wihstutz, 2011). Most young carers provide care for a parent with a chronic illness or disability, but a smaller number care for siblings (Dearden and Becker, 2004). Within this literature, it has consistently been found that the nature of the condition of the person being cared for influenced the type of care provided (Aldridge and Becker, 1993; Frank, 2002; Dearden and Becker, 2004; Smyth *et al.*, 2011). Girls have been found to provide more care than boys (Aldridge and Becker, 1993; Dearden and Becker, 2004). Some have also argued that older children take on more caring responsibilities (Dearden and Becker, 2004; Smyth *et al.*, 2011), but others have found that age is not necessarily a factor that influences the level of care provided (Aldridge and Becker, 1993). Furthermore, social circumstances have been found to impact on children's care work, as having a larger social support network appears to reduce children's workload (Dearden and Becker, 2004; Aldridge, 2008; Smyth *et al.*, 2011).

The majority of the research on young carers is policy focused and within this literature caring for siblings has not been explored in detail. Moreover, to date, there has been no research on children who are not officially recognised as young carers but still provide care for family members with chronic conditions. As a result, one aim for this study is to begin to address this gap in the literature by answering the following research question: *To what extent do siblings contribute to informal care practices associated with their brother or sister's epilepsy?*

Continuing with the theme that family practices are the foundation of family life, the focus of this literature review now shifts to look at food and eating practices within the family. Morgan (2011) himself argues that there is a close connection between families and food. Indeed, food is an important aspect of kinship, as eating together helps to reproduce the family and strengthen family relationships (Lupton, 1996; Mintz and Du Bois, 2002; Coveney, 2006; Cheng *et al.*, 2007).

2.3.4 Food in the Family

Food is not merely a source of nutrients and fuel for the body; 'the myriad of ways in which people acquire and eat food are reminders of the complex social qualities of food and eating' (Delormier *et al.*, 2009: 224). Indeed, it is widely asserted that the food we eat is largely determined by cultural values and that individuals eat as much with their minds as with their mouths (DeVault, 1991; Delormier *et al.*, 2009; Wills *et al.*, 2011). Consequently, it is argued that the meanings attached to foods are as important as the taste and texture of the food itself (Beardsworth and Keil, 1997; Rozin *et al.*, 1997; Counihan, 1999).

People often use ideas of 'good' and 'bad' foods to distinguish between those that are perceived to be beneficial to one's health and those that are seen to be detrimental (Counihan, 1999; Lupton, 2005). Foods that are high in sugar, and particularly those with a high fat content, are viewed

as 'bad' foods (Lupton and Chapman, 1995; Lupton, 1996, 2005; Counihan, 1999). Health campaigns stretching back to the early 1980s recommended that people should reduce their fat intake (Beardsworth and Keil, 1997) and food policies relating to fat reduction in individuals' diets have become so commonplace that they are now taken for granted (Mennell *et al.*, 1992; Blank *et al.*, 2009). Furthermore, although health professionals distinguish between 'good' fats and 'bad' fats, the lay public often group all fats together (Lupton, 2005). The high fat content of the ketogenic diet, described in Chapter One, therefore contradicts assumptions about the types of food that should be eaten.

Ideas about 'good' and 'bad' foods can result in judgements being made about others based on the types of food they eat. When judgements are made the meanings attached to particular foods are transferred onto the people who eat them; those who consume 'bad' foods are seen to be bad people who lack self-control (Backett, 1992; Lupton, 1996, 2005; Beardsworth and Keil, 1997; Rozin *et al.*, 1997; Counihan, 1999; Saguy, 2013). Similarly, judgements can be made about parents, particularly mothers, based on the types of food they feed their children (Dixon and Banwell, 2004; Saguy, 2013; Harman and Cappellini, 2015). It may therefore be the case that parents of children on the ketogenic diet feel that others judge them as a result of their child's high fat diet.

Food is also important for parents because it is argued that love and care are displayed through feeding practices (DeVault, 1991; Lupton, 1996; Kaplan, 2000; Devine *et al.*, 2003; Warin *et al.*, 2008; Curtis *et al.*, 2009; James *et al.*, 2009; Metcalfe *et al.*, 2009). However, as much as parents want to please their children, they also feel responsible for the provision of healthy meals (Cook, 2009a, 2009b; Stapleton and Keenan, 2009).

Furthermore, it has been argued that there has been a shift in parenting philosophy, whereby parents now feel that children should be able to express their own opinions and food should not be forced upon them

(Dixon and Banwell, 2004; Coveney, 2006). It appears that this philosophy is particularly prevalent among working class families, where it has been found that children's food choices are readily accepted (Backett-Milburn *et al.*, 2006) and the development of autonomy is encouraged (Wills *et al.*, 2011). These findings illustrate that the meanings attached to food and eating vary among different classes due to the habitus – acquired dispositions and tastes – of each group (Bourdieu, 1984; Wills *et al.*, 2011). It may be the case that the ketogenic diet limits parents' ability to satisfy their child's food requests because of the nature of the diet. Furthermore, due to fat having a high calorific content, portion sizes of ketogenic meals are often smaller than people are used to, meaning that parents may feel they are not providing their child with enough food. Therefore, it is possible that the nature of the diet may cause parents, particularly working class parents, to feel conflicted between implementing the diet and fulfilling their child's food desires.

However, although Coveney (2004) found differences in the way in which high-income and low-income parents viewed their children's diets, his findings suggest that the ketogenic diet may be more problematic for middle class parents. He found that those in the high-income group spoke about specific nutrients in different foods and worried about illnesses that could be caused by the foods their children consumed. In contrast, those in the low-income group felt that their children's diets were adequate based on their children's outward appearance, level of stamina and lack of illness. Therefore, children's food consumption appears to be viewed as more of a risk by those in higher socioeconomic groups. Consequently, as well as potentially being problematic for working class parents, implementing the ketogenic diet may, for different reasons, also cause conflicting feelings in parents of higher socioeconomic status.

Food also carries significance for the family as a whole. Although it is acknowledged that family meals can be a site of conflict (Wilk, 2010), it has been argued that the family meal is an important way of 'doing family' and,

as a result, is still something that many families aspire to (Blake *et al.*, 2009; James *et al.*, 2009; Metcalfe *et al.*, 2009). The family meal is significant for families because it is seen as a social event that brings all family members together and symbolises cohesion (Stapleton and Keenan, 2009). Parents also believe that the family meal is characterised by the consumption of 'proper food' – that which is homemade rather than convenience food (Robinson, 2000; Blake *et al.*, 2009; James *et al.*, 2009).

Despite this prevalent notion of the family meal, Gallegos *et al.* (2011) note that just as definitions of the 'family' are fluid, so too are definitions of a 'meal'. They argue that the family meal is adaptable and takes a number of forms. For example, the majority of the 625 young people in their study felt that all family members being present was the defining feature of the family meal but only half consumed their family meal around a table. As well as this, many did not believe that the food served had to be home-cooked for the meal to be considered a family meal. Gallegos *et al.* (2011) conclude that the current view of the family meal may be different to traditional definitions but, nevertheless, it is still an important feature of family life for parents and young people. There is scope for the ketogenic diet to contradict notions of the family meal because family members are likely to be eating different foods; however, as individuals' interpretations of the family meal vary, whether parents feel the diet does in fact contradict this norm is unknown.

The above literature illustrates the importance that families place on sharing food and eating together. Thus, it is probably unsurprising that research focusing on families' responses to the use of diet by a family member for medical reasons indicates that these other family members often assimilate dietary changes by adjusting their own food consumption. This response has been found in families where one family member had diabetes (Kelleher, 1988; Maclean, 1991), a nut allergy (Pitchforth *et al.*, 2011), coeliac disease or coronary heart disease (Gregory, 2005). An alternative response, found in families where a child had coeliac disease,

was to demedicalise the diet by treating food consumption as ‘a matter of choice rather than prescription’ (Veen *et al.*, 2013: 592). It is unlikely that other family members would be able to incorporate the same dietary changes as the child on the ketogenic diet because the diet has to be medically monitored. It is therefore important to consider how the ketogenic diet is incorporated into family life.

This subsection has shown that food and eating have a multitude of meanings attached to them; however, the ketogenic diet conflicts with a number of these meanings. For example, the diet is high in fat – a ‘bad’ food – which may make parents feel apprehensive about feeding their child such foods. Additionally, restrictions on the types of foods that children can eat means that parents may not be able to display their love for their child through food. Furthermore, it is unlikely that the diet can be taken on by all family members or that the child on the diet will be able to eat the same foods as their family members. As the ketogenic diet is yet to be researched from a sociological perspective, the interesting question can be raised: *How does implementing the ketogenic diet affect the meanings attached to foods?*

This subsection has introduced the ways in which families manage dietary treatments. The next section continues with the theme of experiences of chronic conditions and treatment by exploring adults’ experiences of chronic illness.

2.4 The Experience of Chronic illness

It has been noted that experiences of illness vary over the life course (James and Hockey, 2007). It is therefore necessary to consider children’s experiences separately from those of adults. However, there is a limited amount of literature detailing children’s experiences of chronic illness. Consequently literature describing adults’ experiences of chronic illness is drawn upon throughout this section. To begin, Bury’s (1982) concept of biographical disruption is introduced. Next, the literature surrounding

experiences of uncertainty is reviewed. Following on from this, the concept of stigma is explored because it has been found to encapsulate adults' experiences of living with epilepsy. Building on the experience of chronic illness, this section ends with a discussion of the meanings individuals attached to medications.

2.4.1 Biographical Disruption

Bury (1982) developed the concept of 'biographical disruption' in his work on adults with rheumatoid arthritis who ranged in age from their early 20s to late 60s. In using this concept he asserts that 'illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted' (Bury, 1982: 169). Bury (1982) goes on to note that there are three aspects to biographical disruption: taken for granted behaviours are disrupted, as are the explanatory systems used by individuals leading to a reconsideration of the individual's biography, and finally, people mobilise resources and respond to the disruption. In his study, Bury (1982) found that arthritis was a condition that a lot of people associated with old age. As a result, many of his participants felt their biography had been disrupted as they were no longer following the 'normal' chronological trajectory, but rather, were ageing prematurely. Bury and Holme (1991) later introduced the concept of the 'social clock' to explain how individuals have an idea of when during the life course certain conditions will occur.

Although biographical disruption has been demonstrated to be a useful concept, Simon Williams (2000) argues that it cannot be used in reference to all experiences of chronic illness. Rather, Williams (2000) asserts that the context and timing of chronic illness need to be taken into consideration, as some experience chronic illness as biographical continuity rather than biographical disruption. For example, older individuals with osteoarthritis in Sanders *et al.*'s (2002) study felt that the condition was to be expected as a result of their stage in the life course and/or as a

consequence of hardship in their past. As a result, these individuals viewed chronic illness as a normal aspect of their biography. Similarly, Faircloth *et al.* (2004) found that older individuals who had experienced a stroke also felt this illness experience was to be expected due to their age. Additionally, Monaghan and Gabe (2015) built on Williams (2000) critique of biographical disruption when they studied young people with mild to moderate asthma. They argued that the young people who participated in their research described asthma as biographical contingency, highlighting the way in which the varying severity of symptoms can impact on the illness experience. Monaghan and Gabe (2015) also illustrate that the young people did not feel that asthma dictated their lives, rather their age and personal circumstances provided them with more pressing concerns.

Furthermore, Simon Williams (2000) has specifically questioned the extent to which the concept of biographical disruption can be employed to describe the experience of chronic illness among children who have a condition from birth or early childhood. He argues that biographical disruption is based on an 'adult-centred model of illness' (2000: 49), and that:

Compared to socially-set standards and cultural prescriptions of 'normality', moreover, the lives of these individuals may appear (profoundly) disrupted. Yet, phenomenologically and existentially speaking, it remains the case that these biographies have not, in any real or significant sense, *shifted*. (2000: 50 original emphasis)

These studies illustrate that age is an important factor to consider when attempting to understand individuals' experiences of chronic conditions, particularly around onset and diagnosis. Next, experiences of uncertainty are considered because epilepsy is a particularly unpredictable condition.

2.4.2 Uncertainty

It has been argued that uncertainty is an inherent aspect of medicine because when scientific advances resolve some uncertainties, they also create new ones (Fox, 2000). As a result, although the content of clinical uncertainty may change, it continues to exist. Uncertainty in medical knowledge can have implications for the illness experience. Adamson (1997) draws a distinction between 'existential' and 'clinical' uncertainty, and argues that these two types of uncertainty can influence one another. He defines existential uncertainty as a 'form of uncertainty which is experienced privately by the individual patient upon the realisation that the future life of his or her mind, body and self is in jeopardy' (1997: 134); and clinical uncertainty as the uncertainty of medical professionals who do not have the necessary knowledge to diagnose a condition or give a prognosis.

However, Davis (1960) notes that even when medical professionals do have the relevant information, it is not always passed on to patients. Indeed, he distinguishes between what he calls 'real' and 'functional' uncertainty. In his research on children with poliomyelitis, Davis (1960) found that to begin with doctors were often genuinely uncertain regarding prognosis (real uncertainty), but that when they were able to make an informed prognosis families were not informed and instead were kept optimistically uncertain (functional uncertainty).

Davis (1960) is one of the few researchers who has explicitly explored the uncertainty experienced by the family members of a person with a chronic condition. On the other hand, existential uncertainty from the patient's perspective has been researched more extensively and seems to be a common experience for those with a number of conditions. Indeed, experiences of uncertainty have been explored from the perspective of people with advanced-stage cancer (Brown and de Graaf, 2013), chronic pain (Honkasalo, 2008), back pain (Lillrank, 2003; Broom *et al.*, 2015), colitis (Kelly, 1992), Parkinson's disease (Pinder, 1988), those undergoing

cervical screening (Howson, 2001) and those conducting breast self-exams (Babrow and Kline, 2000). For many of the individuals with a chronic illness in the studies listed above, it was uncertainty regarding the timing and severity of symptoms that individuals found most problematic.

However, diagnostic uncertainty can also be stressful for individuals. It has been argued that diagnoses are valued because they validate illness, offer an explanation and provide access to appropriate treatment (Jutel, 2009, 2011; Jutel and Nettleton, 2011). Consequently, when a diagnosis is not given this can be distressing (Jutel, 2009, 2011). For instance, Dumit (2006) studied those with emergent illnesses and Lillrank (2003) explored the experiences of women with chronic back pain; both found ongoing uncertainty as a result of not receiving a diagnosis was particularly troubling for these individuals. Similarly, Nettleton found that those with medically unexplained symptoms 'endure[d] a significant degree of embodied doubt and uncertainty' (2006: 1167), which led to ambivalence directed towards the medical profession. As there is a considerable degree of uncertainty related to the diagnosis of epilepsy, described in the clinical overview presented in Chapter One, there is potential for diagnostic uncertainty to feature in families' experiences of childhood epilepsy.

Furthermore, similarly to those with other chronic conditions there is a high level of uncertainty inherent in epilepsy related to the timing of symptoms. For instance, seizures often occur without any warning (Schneider and Conrad, 1983). For many people with epilepsy this type of uncertainty is the most troubling (Scambler, 1989). Indeed, Reis (2001) argues that for people with epilepsy, the condition is not just about when seizures happen, times without seizures are also dictated by the condition, as individuals have to consider the possibility that a seizure could occur at any time. Additionally, there is the added uncertainty for children with epilepsy and their parents as to whether the child will grow out of the condition (Schneider and Conrad, 1983). These studies indicate that uncertainty is a key feature of experiences of epilepsy. Another concept that

has featured prominently in the literature on epilepsy is stigma, which is discussed below.

2.4.3 Stigma

It is important to note that the attributes and conditions that are stigmatised are the result of social norms. Essentially, an attribute can only be seen as unacceptable if it contradicts what is seen as 'normal'; and consequently ideas of what is 'normal' can only exist if there are instances and the possibility of the 'abnormal' being present (Scambler, 2009).

In Goffman's discussion of stigma, he identifies three different types of stigma: 'abnormalities of the body ... blemishes of individual character ... [and] tribal stigma of race, nation, and religion' (1963: 14). Goffman (1963) also distinguishes between people who are 'discredited' and those who are 'discreditable'. For those who are discredited, the stigmatising attribute is obvious and immediately known to others, whereas for those who are discreditable, the stigmatising attribute is not obvious to the outside world and therefore, potentially, can be hidden. However, individuals who choose to hide their stigmatising attribute run the risk of becoming discredited should this be discovered.

It has been found that many adults with epilepsy believe the condition is stigmatised (Schneider and Conrad, 1983; Scambler and Hopkins, 1986, 1988; Scambler, 1994). However, Scambler and Hopkins (1986) argue that there is little evidence to support the idea that epilepsy is stigmatised by the public. On reviewing a number of studies they concluded that the overall trend was for a reduced level of stigma being attached to epilepsy over time. Jacoby *et al.* (2004) concur as they surveyed 71,600 members of the general public and found that, on the whole, people were generally well informed and had favourable attitudes towards people with epilepsy.

However, many people with epilepsy still *feel* stigmatised as a result of the condition (Scambler, 1994). Baker (2002) surveyed people with epilepsy in 10 European countries and found that of 6,156 respondents 46% felt stigmatised. When feelings of stigmatisation were broken down by country the lowest rate was in the Netherlands (27%) and the highest rate was in France (62%); the UK also had one of the highest rates, as over half (51%) felt stigmatised by the condition. However, the sample for this study was drawn from epilepsy support groups and may, therefore, over represent people who feel they need help coping with the condition.

Scambler and Hopkins (1986, 1988) built on Goffman's (1963) work when they distinguished between enacted and felt stigma. They argue that enacted stigma involves actual instances of discrimination, whereas felt stigma is a sense of shame felt by people as a result of having epilepsy and incorporates the fear of enacted stigma. They went on to assert that people with epilepsy in the UK were predominantly limited through felt stigma and that there was actually little evidence of enacted stigma when those with epilepsy were asked to give specific examples. This is supported by Jacoby (1994), who found that only 2% of 607 people with epilepsy were able to give an example of being treated unfairly at work in the previous two years as a result of their epilepsy.

It has been found that certain features of the condition can result in higher levels of felt stigma. For example, Baker *et al.* (1999) found that frequent seizures, experiencing side effects from AEDs and injuries as a result of seizures were associated with higher levels of felt stigma. Similarly, Jacoby (1992) found that people whose epilepsy was in remission had lower levels of felt stigma than those with active epilepsy. However, 14% of those in remission still felt stigmatised by the condition (Jacoby, 1994), indicating that felt stigma is not wholly the result of the clinical manifestation of the condition.

For those who do feel stigmatised by the condition, seizures and the label of epilepsy can have a profound impact on the self. Schneider and Conrad (1983) found that adults with epilepsy in America saw seizures as a threat to, and in some cases, a suspension of the self, as they had no control over them. Additionally, they found that the stigma associated with epilepsy meant that people carried the burden of feeling that they were in some way 'spoiled'. More recently, Shostak and Fox (2012) found that people with epilepsy in the United States still felt the condition was stigmatised to an extent. However, they also felt that levels of enacted stigma had reduced in comparison to the levels of enacted stigma experienced by their family members in the previous generation who also had the condition.

The above discussion introduces the concepts of biographical disruption, uncertainty and stigma. Each of these concepts has been found to effectively encompass the illness experience of adults with different conditions. This review of the literature also illustrates how uncertainty and stigma in particular can be useful in understanding the experiences of adults with epilepsy. Additionally, the research that has used biographical disruption as an explanatory tool demonstrates the importance of considering an individual's stage in the life course. Consequently, the following question can be asked: *How do children and their family members experience living with childhood epilepsy?*

Treatment also forms an important part of the illness experience. Above, the ketogenic diet was considered in relation to the meanings families attach to food and eating. Medications are another type of treatment for childhood epilepsy that will be focused on within this thesis. Below, the research on the meanings attached to medications is explored.

2.4.4 The Meanings Attached to Medications

In the same way that there are meanings associated with different foods, meanings are also attached to medications (Cohen *et al.*, 2001). Indeed, Britten argues that:

Over the course of several millennia, medicines and medicine use have acquired a range of symbolic and cultural meanings. The diversity of these meanings still reflects the ancient Greek word *pharmakon*, which denoted cure, poison and magical charm. (2008: 45)

It seems to be that people often associate the term 'medicine' with positive connotations, whereas 'drugs' are viewed negatively (Britten, 1996, 2008). Furthermore, over the counter medicines tend to be seen as safer than prescription medication, as the general consensus is that these treatments would not be so readily available if they were risky (Bissell *et al.*, 2001).

A number of researchers have looked at the varying meanings that individuals attach to specific prescription medications. For example, when studying psychotropic drugs, Helman (1981) found that these medications were viewed as either tonic, fuel or food. Helman (1981) argued that those who saw psychotropic drugs as a tonic used the drugs to self-medicate and conveyed a sense of choice over their medication use. Those who saw the drugs as a fuel felt these medications helped them fulfil their social relationships, but shared responsibility for their successes with the drugs. In contrast, those who saw the drugs as food felt they needed these medications in order to survive, as without them they could not function as sane independent people. However, Gabe and Lipshitz-Phillips (1982, 1984) found that women who saw benzodiazepines as a 'life-line' commonly displayed ambivalence towards their medications. For instance, one participant referred to the drugs as an 'evil necessity'. Indeed, although these women conceded that benzodiazepines helped them, they did not view them wholly positively because they feared becoming dependent on the drugs.

Ambivalence regarding medications is often linked to the side effects that accompany medication use (Pound *et al.*, 2005; Britten, 2008; Chamberlain *et al.*, 2011) and the perception that they are not natural (Gabe and Lipshitz-Phillips, 1984; Britten, 1996; Whyte *et al.*, 2002). Being prescribed drugs for a chronic condition has also been linked to the feeling of a loss of control because people feel they have lost their independence and are now reliant on medications (Conrad, 1985; Shoemaker and Ramalho de Oliveira, 2008). Moreover, the view that medications are unnatural, and consequently harmful, in addition to long-term use, can lead to individuals feeling concerned about the use of medications for chronic conditions (Webster *et al.*, 2009). Indeed, it has been found that there is widespread resistance regarding medication use (Gabe and Lipshitz-Phillips, 1982; Pound *et al.*, 2005). However, Chamberlain *et al.* (2011) note that resistance is a complex phenomenon, as the adults in their study would sometimes reject one drug while at the same time accepting another.

Despite negative meanings being attached to a number of medications, it has also been found that they can be viewed positively. Indeed, Shoemaker and Ramalho de Oliveira (2008) argue that when a medication helps to relieve debilitating symptoms it can be seen as a magic elixir. More generally, it has been found that medications are valued because they promise a return to health and offer a means of regaining control (Whyte *et al.*, 2002; van der Geest, 2010). Furthermore, medications can be viewed positively because they allow treatment to remain personal as drugs can be administered discretely (van der Geest and Whyte, 1989; van der Geest, 2010). This is particularly likely to be the case for those with stigmatised conditions, as Goffman (1963) argues that medications can be stigma symbols.

In relation to children and medications, Whyte *et al.*, (2002) found that mothers in the Philippines saw drops as suitable for infants, syrups were deemed to be for children and tablets were seen to be adults' medication. However, despite the wealth of knowledge on the meanings

adults attach to medications, little has been written regarding children's views on medications. Almarsdóttir and Zimmer (1998) explored American children's knowledge of medications and the extent to which they retained information from televised adverts. Additionally, Christensen (1998) found that when children administered their own medication they sometimes gained status with their peers, as this practice was seen to denote responsibility.

There is, however, no research detailing children's views of AEDs. Conrad (1985) found that adults saw their epilepsy medications as a 'ticket to normality' because, when the drugs were effective, individuals had fewer seizures, which meant they experienced fewer interruptions to their daily lives. However, it has also been found that there are problems associated with AED treatment. Often the medications prescribed to control seizures caused side effects, which many people found to be disruptive to their ordinary social conduct (West, 1976; Conrad, 1985; Elliot *et al.*, 2005; Loring, 2005). The side effects that individuals described as most troublesome were those that affected their social interactions (Conrad, 1985). For example, drowsiness and impaired concentration were two of the most problematic side effects for adults with epilepsy (Scambler, 1989). It would be interesting to know how side effects impact on the meanings children and their family members ascribe to medications for epilepsy, and how children view their treatment more generally. Consequently, the following research question can be asked: *How do family members view medications for childhood epilepsy?*

Treatment is only one means of managing chronic conditions. The non-medical management techniques used by adults with chronic illnesses will now be explored.

2.5 Non-Medical Management of Chronic Illness

People manage chronic conditions in a number of ways. Some management techniques are specific to certain conditions; however, others are more general and have been used by people with a number of chronic illnesses. Firstly, the ways in which people manage the uncertainties related to chronic conditions will be addressed. Next, following on from the work on stigma, outlined above, Goffman's (1963) concepts of 'passing' and 'covering' will be introduced.

2.5.1 Responding to Uncertainty

Zinn (2008) contends that responses to uncertainty fall on a continuum consisting of three broad categories: rational, non-rational and what he terms 'in-between' strategies. He argues a rational response to uncertainty is to assess risk by weighing up the pros and cons of a given situation and calculating an appropriate response, whereas non-rational strategies include relying on belief, hope and faith. Zinn (2008) claims in-between strategies, such as trust and intuition, fall between rational and non-rational because although they incorporate knowledge, they are also influenced by individuals' beliefs and feelings. In spite of defining some responses to uncertainty as non-rational, Zinn (2008) does recognise that these can be useful, as they enable people to act in situations that may be perceived to be hopeless.

Petersen and Wilkinson (2015) argue that hope in particular is a neglected area, but individualised and privatised forms of hope are extremely pertinent to contemporary studies of health and illness. Indeed, in their recent research focusing on advanced-stage cancer patients, Brown and de Graaf (2013), Brown *et al.* (2014) and Chen *et al.* (2015) all found that individuals often responded to uncertainty by hoping for a positive future. Brown and de Graaf (2013) argue that uncertainty results in future time being malleable, which means that there is space not only to imagine a

future, but to be optimistic about that future. However, Brown *et al.* (2014) explored the tensions that exist when hoping. For instance, they highlight ontological tensions and argue that 'the uneasy combining of negative, realistic or modest expectations with more bold or highly positive imagined outcomes for the future is central to what it means to hope' (Brown *et al.*, 2014: 13). Through such analysis, Brown *et al.* were able to highlight the 'empirical messiness of hope' (2014: 15).

A further response to uncertainty surrounding the future, which Brown and de Graaf discuss, is the way in which individuals may 'bracket off all but the immediate future' (2013: 553). In doing so these people could look forward to future possibilities while feeling they were being realistic. Similarly, those with chronic back pain or heart disease (Honkasalo, 2008) and Chinese people with advanced cancer (Chen *et al.*, 2015) talked about taking one day at a time.

In relation to epilepsy, Schneider and Conrad (1983) found that adults tried to manage uncertainty related to the timing of their seizures by producing theories regarding why they had had a seizure and, thereby, trying to create certainty. Beyond this technique, much that has been written on epilepsy has focused on how people try to manage the possibility of being stigmatised if they were to have a seizure. Two ways in which people have been found to manage stigmatised conditions is through passing and covering, which are discussed in the following subsection.

2.5.2 Passing and Covering

Goffman (1963) coined the terms 'passing' and 'covering'. He argues passing involves not disclosing the stigmatised attribute and presenting the self to others as 'normal'. Covering, on the other hand, is when the stigmatising attribute is known to others but the person with the stigma attempts to ensure that the stigmatised attribute is given as little attention as possible. Goffman (1963) argues that people will often try to pass

because of the rewards associated with being 'normal', but when they are unable to they are likely to try to cover. He goes on to assert that those who pass and those who cover use similar techniques because a technique that helps hide a stigmatised attribute is also likely to keep it out of focus.

People with a number of conditions try to pass in order to minimise the impact of their illness on their social interactions. For example, Kelly (1992) found that people with colitis often avoided eating or drinking in public settings to prevent the onset of symptoms and the stigma associated with these symptoms. Similarly, Jobling (1988) found that those with psoriasis used a number of techniques in order to pass, such as wearing clothing that covered areas of skin that were affected by the condition and using their own sheets in hotels to avoid leaving flakes of skin or grease from ointment on the sheets. Therefore, people are likely to attempt to pass when their condition is stigmatised, but the techniques they employ vary depending on the symptoms of the condition.

Goffman (1963) also argues that people may be assisted by the 'wise' in order to pass. The wise are people who are knowledgeable about the person's condition. Charmaz's (1991) made a similar argument, but instead used the term 'alert assistant'. Clare Williams (2000) further defined this concept and used it to describe the often invisible work carried out by mothers of teenage boys with asthma or diabetes. She explained how these mothers would identify or anticipate the needs of their son and then meet those needs. For example, mothers would negotiate between their son's public and private worlds, which meant the boys did not have to disclose information about their condition themselves.

Passing is the primary way in which it has been found that people manage epilepsy (Schneider and Conrad, 1981, 1983; Scambler and Hopkins, 1986, 1988; Scambler, 1989, 2011; Iphofen, 1990; West, 1990). For instance, Schneider and Conrad (1983) found that adults would find a 'safe place' out of the sight of others when they experienced signs indicating

that a seizure was imminent. If an individual did not experience these warning signs and had a potentially discrediting public seizure, they would often continue trying to pass, or cover if this was not possible. In the case of tonic clonic seizures people attributed them to other illnesses that they believed to be less stigmatised, or if they had an absence seizure they would excuse themselves as being tired and not concentrating (Schneider and Conrad, 1983). Similarly, in Iphofen's (1990) case study of a woman with absence seizures, it was found that she habitually began to say 'sorry' whenever she recovered from a seizure in order to maintain her social interactions.

However, it has also been noted that it is not as simple as someone being 'in' or 'out' of the epilepsy closet (Schneider and Conrad, 1980). Rather, Schneider and Conrad (1980) argue that the closet of epilepsy has a revolving door and that people move between concealment and disclosure depending on the situation. For example, when it is likely that someone will witness a seizure, people tend to disclose their condition (Schneider and Conrad, 1983).

The literature on children's experiences of chronic illness will now be explored, with particular interest being paid to children with epilepsy. As there is a limited amount of literature available in this area, the concepts introduced above in relation to adults' experiences of chronic illness will be drawn upon.

2.6 The Ways in which Children Experience and Manage Chronic Illness

It has been found that chronic conditions can disrupt children's lives. Gabe *et al.* (2002) and Nocon and Booth (1990) studied children with asthma and found that their daily lives and social interactions were affected by their condition. Children sometimes had to take time off school and their participation in sport was restricted. Many were also unable to visit certain places due to high pollen levels or the houses of friends who had pets with

fur that could trigger an attack. Some of the children were also unable to attend 'Bonfire Night' due to the smoke in the air. These limitations to their daily lives provoked a number of emotions in the children, such as anger and irritation (Gabe *et al.*, 2002).

The majority of the research carried out on epilepsy has considered the experience of adults with the condition (Schneider and Conrad, 1983; Conrad, 1985; Scambler and Hopkins, 1986, 1988; Scambler, 1989; Iphofen, 1990; Shostak *et al.*, 2011; Shostak and Fox, 2012). Although some of these studies report the experience of epilepsy during childhood, these descriptions are based on adults' recollections. As children's experiences and adults' recollections of their childhoods do not always equate (Hockey and James, 1993; Thorne, 1993), adults' accounts of epilepsy during childhood may not be an accurate representation of children's experiences of epilepsy.

Weinbren and Gill (1998) and Admi and Shaham (2007) conducted the only two studies that have focused on children's/young people's experiences of epilepsy. Weinbren and Gill (1998) interviewed 6 children with epilepsy in the UK aged between 8 and 12 years old and asked them to draw pictures about what epilepsy meant to them. It was found that the children believed epilepsy was an intrusion on their lives because they felt it affected their school life, holidays, friends and family members. However, Weinbren and Gill (1998) did not give details regarding why the children felt this way. The children in this study also described feeling different from others and from a previous self, indicating that, much like adults, children can also feel stigmatised by the condition.

Furthermore, James (1993) found that conformity was important among children. When studying children with diabetes Alderson *et al.* (2006) noted that one child was teased by her sister for not being able to eat sweets. Similarly, the children in Weinbren and Gill's (1998) study described being teased by their peers at school as a result of their epilepsy.

However, there is only limited information regarding children's experiences of epilepsy because Weinbren and Gill's (1998) sample consisted of six children who experienced only two types of seizures. Furthermore, they do not go into detail about why children felt the way they did.

Children in Western societies are often viewed as incompetent (Christensen, 1998; Hutchby and Moran-Ellis, 1998; Alderson, 2007). However, it has been found that children aged between nine and 10 years old and those aged 15-16 possess significant health-related knowledge and have a considerable understanding of the causes and prevention of cancer, particularly lung cancer (Oakley *et al.*, 1995; Bendelow *et al.*, 1996; Williams and Bendelow, 2000). Furthermore, Alderson *et al.* (2006) and Alderson (2007) found that children with chronic illnesses were highly proficient in managing their conditions, even those who were very young. Examples of children's and young people's ability to manage chronic conditions include those with coeliac disease (Olsson *et al.*, 2009), thalassaemia major (Atkin and Ahmad, 2002) and diabetes (Alderson *et al.*, 2006) who all attempted to normalise their lives as much as possible because they did not want their respective illnesses to be defining features of their lives or identities. Similarly, Admi and Shaham detailed the experiences of young people with epilepsy in Israel and found that they did not want epilepsy to dictate their lives and they viewed themselves as 'normal people who were coping with health problems' (2007: 1182). As there are vast cultural differences between Israel and the UK, the results of this study may not be generalisable to children with epilepsy in the UK. However, they do seem to align with the views of young people with other conditions.

Furthermore, the children in Weinbren and Gill's (1998) study also talked about wanting to be treated normally by others. However, in contrast to the young people described by Admi and Shaham (2007), Weinbren and Gill (1998) explained that the children in their study often concealed their condition from others and generally only felt comfortable discussing their epilepsy with close family members. As there is a discrepancy between

these two studies regarding how children with epilepsy manage the condition, and because it has been found that epilepsy is less stigmatised than it was in the past, it would be interesting to know: *To what extent is concealment used as a management strategy for childhood epilepsy in contemporary society?* This question will be returned to later on when discussing the management of chronic conditions within the family.

The literature described above on family practices and family relationships, and also that on chronic illness, will now be brought together by considering the impact chronic illness can have on family life.

2.7 The Impact of Chronic Illness on Family Practices and Family Relationships

Employing Morgan's (1996) concept of family practices is a useful way of assessing how family life can be altered as a result of chronic illness. As there is limited information on the impact of epilepsy on family life, this section will incorporate literature on families with children with other chronic conditions in order to postulate how having a child with epilepsy may impact on family practices and, consequently, family relationships.

Similarly to the research cited above that described how children with asthma had their lives disrupted by the condition, the lives of family members can also be disrupted. For example, families may have holidays or days out interrupted when the child's symptoms recur (Nocon and Booth, 1990; Bluebond-Langer, 1991; Prout *et al.*, 1999; Barlow and Ellard, 2006). Parents' social lives may also be inhibited either because children cannot participate or because parents are reluctant to use baby sitters due to the child's care needs (Hill and Zimmerman, 1995). Furthermore, Timmermans and Freidin (2007) found that parents of children with asthma were called away from work on occasion to collect their child from school if the child had experienced an asthma attack or if they were wheezing.

Specifically in relation to epilepsy it has been found that the sleeping practices of family members may be altered as a result of having a child with the condition. Williams *et al.* (2000) studied 179 families with a child with epilepsy and found that 22% of children had their sleeping arrangements altered to less independent sleeping arrangements after diagnosis. Williams *et al.* (2000) defined 'less independent sleeping arrangements' as children's sleeping arrangements being changed from sleeping in a room alone to sleeping in the same room as a sibling or parent, or sharing a bed with a family member. These changes were made as a result of parents worrying about children having a seizure during the night and had no relation to the child's age or the severity of their epilepsy. However, these changes did correlate with parental perceptions of seizure control i.e. if parents *felt* the child's epilepsy was uncontrolled they were more likely to alter their sleeping arrangements to less independent ones.

Children's and parents' differing views on how a condition should be managed can cause tension in the parent-child relationship. For instance, Atkin and Ahmad (2002) found that young people with thalassaemia major rejected their parents' ideas of what was in their best interest when these opinions conflicted with their attempts at normality. This therefore caused disagreements between parents and their children.

Similarly, as a result of concern over the occurrence of seizures, parents may restrict their child's activity participation. Indeed, Oostrom *et al.* (2001) found that of 69 parents whose child had been diagnosed with epilepsy in the previous 48 hours, almost half (48%) felt they could not continue habitual parenting practices. For example, as children's seizures are unpredictable, their parents may supervise them to a greater extent than they would their siblings or peers (Reis, 2001). Scambler and Hopkins (1988) found that parental overprotection was the most common cause of resentment in children with epilepsy (based on adults' recollections of their childhoods). If parents place restrictive rules on children or provide more supervision than the child's peers receive due to concern for the child's

safety, this may cause tension in the parent-child relationship, particularly as children get older.

Siblings' lives may be affected by having a brother or sister with a chronic condition or disability. For example, Stalker and Connors (2004) found that in families where parents only allowed activities that everyone could join in with, some siblings were prevented from participating in age appropriate activities. Additionally, in families with a child with cancer, Dixon-Woods *et al.* (2005) found that siblings had difficulty defining their role within the family and, as a result, experienced emotional and developmental problems.

Furthermore, siblings may also experience jealousy about the attention the chronically ill child receives, which may impact on their relationship with their parents and/or their chronically ill sibling (Nocon and Booth, 1990; Bluebond-Langer, 1991; Dixon-Woods *et al.*, 2005). As emotions are, in part, shaped by social and cultural forces (Hochschild, 1998; Williams and Bendelow, 1998; Barbalet, 2002) it would be of interest to know whether siblings of children with epilepsy experience jealousy; and if so, whether this jealousy impacts on the sibling's relationship with their brother or sister and also their relationship with their parents. Research on how chronic illness can impact on family relationships is limited and although Scambler (1983, 1989) detailed how epilepsy could result in conflict between spouses and young adults and their family members, there is little information specifically regarding the impact of childhood epilepsy on family relationships. This raises the question: *How does childhood epilepsy affect family relationships?*

In the same way that individuals with a chronic illness find ways to manage their condition, families also adapt to living with the chronic conditions of family members. The next section details the ways in which families have been found to manage epilepsy.

2.8 Managing Epilepsy within the Family

It was illustrated earlier in this chapter that people with epilepsy felt stigmatised due to their condition. Scambler and Hopkins (1988) found that stigma was predominantly learnt within the family. Indeed, Schneider and Conrad (1983) concur and argue that parents act as 'stigma coaches' by showing children they were ashamed of their epilepsy, not being willing to talk about it and by encouraging children to conceal the condition.

Similarly to the management techniques used by adults with epilepsy, the main management technique found to be used by families with children with epilepsy was concealment and avoiding situations where the child's epilepsy may be exposed (Scambler and Hopkins, 1988; Scambler, 1989; West, 1990). Parents opted to conceal the child's condition because they felt it was stigmatised and that the stigma could be passed on to all family members if exposed (West, 1990). However, these studies are now dated and Weinbren and Gill (1998) found that although children wanted to conceal their epilepsy, parents tried to encourage children to be open about their condition. These parents predominantly informed others so as to 'prepare' people 'for the shock of witnessing a fit' (Weinbren and Gill, 1998: 66). Yet parents also acknowledged that disclosure could be embarrassing for children and, consequently, did not always inform others about the child's condition. Additionally, Shostak *et al.* (2011) spoke to family members of people with epilepsy and found that they compared the condition to more disabling illnesses and argued that epilepsy was not the worst condition a child could have. This indicates that families may not conceal epilepsy to the extent they did in the past and, consequently, the following questions can again be asked: *How do families manage childhood epilepsy?* And more specifically: *To what extent is concealment used as a management strategy for childhood epilepsy in contemporary society?*

2.9 Conclusion

This chapter has reviewed the sociological literature on: conceptualisations of children and childhood; parenting in a risk society; family practices and family relationships; children who provide informal care; the meanings attached to food and the implementation of dietary alterations within the family; the meanings attached to medications; and, the experience and management of chronic conditions by adults, children and families.

It has been shown that the research on children with epilepsy is limited, as much of the previous research has focused on adults with epilepsy (Schneider and Conrad, 1983; Conrad, 1985; Scambler and Hopkins, 1986, 1988; Scambler, 1989; Iphofen, 1990; Shostak *et al.*, 2011; Shostak and Fox, 2012). There is also some discrepancy regarding the extent to which children with epilepsy and their family members conceal the condition from others. For instance, it has been argued that concealment is the primary means of managing epilepsy within the family (Scambler and Hopkins, 1988; Scambler, 1989; West, 1990) and that children with epilepsy opt to conceal the condition from others (Weinbren and Gill, 1998). However, it has also been argued that epilepsy is less stigmatised than it was in the past (Scambler and Hopkins, 1986; Jacoby *et al.*, 2004; Shostak *et al.*, 2011) and that young people with epilepsy perceive themselves to be 'ordinary people' (Admi and Shaham, 2007).

Furthermore, the ketogenic diet is yet to be researched from a sociological perspective. It has been demonstrated within this literature review that the diet contradicts a number of norms associated with food and eating; for instance, the diet has a high fat content and there are restrictions on the types of food that can be eaten. Moreover, it is unlikely that all family members will be able to take on the same dietary alterations as the child on the diet, which is the primary way in which it has been found that families respond to dietary alterations for other chronic conditions (Kelleher, 1988; Maclean, 1991; Gregory, 2005; Pitchforth *et al.*, 2011).

Additionally, siblings are rarely considered in research on chronic conditions within the family and children's informal care practices have been given little attention (Kosonen, 1996; Morrow, 2008). Although there is a policy-based literature on young carers, the care provided by children who are not young carers is under researched. The meanings children attach to medications is also a neglected area. There are, however, a number of studies addressing the meanings adults attach to medications, and it would be of interest to know how the meanings children and their parents attach to epilepsy medications compare to this body of literature.

Consequently, based on the literature review detailed above, the following research questions have been asked:

- How do children and their family members experience living with childhood epilepsy?
- How do families manage childhood epilepsy?
- To what extent is concealment used as a management strategy for childhood epilepsy in contemporary society?
- How do family members view medications for childhood epilepsy?
- How does implementing the ketogenic diet affect the meanings attached to foods?
- How does childhood epilepsy affect family relationships?
- To what extent do siblings contribute to informal care practices associated with their brother or sister's epilepsy?

The next chapter outlines the methodological approach that was used to answer these research questions.

Chapter Three: Methodology

3.1 Introduction

This chapter describes the methodological approach taken in order to answer the research questions stated in Chapter Two. The chapter is split into seven main sections, the first of which is a brief overview of the sociology of childhood, which informed the research design. The second section then explains the research design in detail; including a discussion of multiple perspective research and the rationale for using a variety of interviews (group interviews, in-depth semi-structured interviews and photo-elicitation interviews). Following on from this, the ethical considerations that were made when planning the research are presented in section three. Next, a description of the recruitment process and the participants is given in section four. In section five the focus turns to the practicalities of data collection and reflections on this process. Section six then outlines the analysis and, lastly, constraints on the research are discussed in section seven.

3.2 Sociology of Childhood

Until the early 1990s the experiences of children were seen to equate to adults' recollections of their childhoods. However, Thorne warns that 'information gleaned from the fields of memory should be treated with scepticism since memories are partial, malleable, and shaped by later experiences as well as by conventions for remembering' (1993: 7). More recently, therefore, it has been argued that experiences of childhood should be accessed directly from children themselves (Hockey and James, 1993; James, 1993; Prout and James, 1997; Alanen, 1998; Hutchby and Moran-Ellis, 1998; Mayall, 1998). Indeed, arguably the main assertion within the sociology of childhood is that:

Children are and must be seen as active in the construction and determination of their own lives, the lives of those around them and of the societies in which they live. (Prout and James, 1997: 8)

Therefore, when researching children's experiences it is important to maximise children's voices by giving children the opportunity to tell their own stories. The full research design and the reasons for employing such an approach are outlined in the following section, including details of children's involvement in the research.

3.3 Research Design

As the funding for this study was from an Economic and Social Research Council collaborative studentship in conjunction with the charity *Epilepsy Action*, the research design had been outlined prior to the student inheriting the project. However, some adaptations were made to the original design, which will be explained throughout this section. To begin, the benefits of using multiple perspective research are discussed. Next, the rationale for employing a qualitative approach is explained. Following on from this, the literature on interviewing children, which informed the research design, is presented. The three types of interviews that were used are then described (group interviews, in-depth semi-structured interviews and autodriveren photo-elicitation interviews). Lastly, some procedural considerations are outlined.

3.3.1 Multiple Perspective Research

It was not only important to include children in this study because they were children, but also because using a multiple perspective approach can help to develop a more rounded picture of family life. Despite the fact that each person in a relationship is likely to view that relationship differently (Mahon *et al.*, 1996; Dekovic and Buist, 2005; Zartler, 2010), Warin *et al.* (2007) argue that some of the previous research undertaken on families is limited, as the experience of only one family member has been sought.

Consequently, it has been argued that it is important to seek multiple perspectives when researching family life (Ribbens-McCarthy *et al.*, 2003; Dekovic and Buist, 2005; Sands and Roer-Strier, 2006; Cook and Hess, 2007; Harden *et al.*, 2010). Indeed, Harden *et al.* argue that:

Through multiple perspective research it is possible to explore the lives, not simply of individuals or standpoints but of families, and to gain a rich understanding of the complex and dynamic ways that children's and parents' everyday lives are experienced as part of family life. (2010: 450)

As this piece of research aimed to gain an understanding of experiences of family life and different family relationships, it was deemed necessary to gain an insight into a number of family members' perspectives. As a result, interviews were carried out with the children with epilepsy, their parents and their siblings. More information regarding the types of interviews that were used is given in subsections 3.3.4, 3.3.5 and 3.3.6, but before that the rationale for taking a qualitative approach is outlined.

3.3.2 Qualitative Approach

It was decided that a range of semi-structured interviews were the most appropriate data collection tools to use, as they enable the researcher to explore in-depth a topic on which little is already known (Fielding and Thomas, 2008). In comparison, questionnaires or structured interviews would not have been suitable because there was no way of knowing prior to the interviews what would be important to the participants. These quantitative methodological approaches may therefore have put an inappropriate framework in place, meaning that the participants would not have been able to express the most salient features of their experiences (Fontana and Frey, 2000; Bryman, 2008).

Semi-structured interviews are also flexible and adaptable (Hollway and Jefferson, 2000; Mason, 2002; Byrne, 2004; Fielding and Thomas, 2008; Gabb, 2008). Utilising flexible data collection tools was particularly

important when researching epilepsy due to the varying types of seizures and treatment methods involved. This approach meant that each interview could be tailored appropriately in order to reveal the varying aspects of the participants' experiences.

The research questions to be addressed are essentially questions of individuals' experiences. It has been argued by numerous researchers that semi-structured interviews reveal people's attitudes, beliefs, values, motivations and feelings (Mason, 2002; Creswell, 2003; Fielding and Thomas, 2008; Kvale and Brinkmann, 2009). The reason these aspects of people's experiences are often revealed is because individuals can talk in depth about their lives, which would not be possible when using a methodological approach comprised of closed questions (Byrne, 2004). Consequently, it was thought that semi-structured interviews would allow the participants to talk in detail about their family circumstances.

Furthermore, it was decided that both group and individual interviews would be used. The original research design that was set out in the funding application included only individual interviews, but the researcher decided to also incorporate group interviews; there were two main reasons for this. Firstly, as one of the focuses of this study is family relationships, it was thought that it would be advantageous for the researcher to observe interactions between the family members. The group interviews consequently gave an insight into the group dynamics and power relations (O'Kane, 2002; Matthews, 2005; Bushin, 2007; Gabb, 2008). Secondly, some people feel more relaxed when talking in a group of people they know (Hill, 2006; Bushin, 2007). This has particularly been found to be the case for children who can feel intimidated when left alone with a stranger (Alderson and Morrow, 2004; Kellett and Ding, 2004). Therefore, the plan was to conduct a group interview with the family members participating in the research first so that they had a chance to get to know the researcher before being alone with her. It was hoped that this would make the children more relaxed during their individual interviews.

One reason for employing individual interviews was because when parents and children have been interviewed together, parents sometimes talk on behalf of their children (Hood *et al.*, 1996; O'Kane, 2002; Bushin, 2007; Harden *et al.*, 2010). Similarly, during group interviews more generally, the voices of dominant characters may hinder the participation of others (O'Kane, 2002; Clark-Ibáñez, 2004; Holland *et al.*, 2010). Participants have also been found to disclose more personal information during individual interviews, as group interviews do not offer the same level of confidentiality (Punch, 2002a; Harden *et al.*, 2010; Holland *et al.*, 2010). Therefore, individual interviews were also included in the research design, as family members may not have wanted to discuss negative aspects of their relationships in one another's company.

Beyond deciding that a qualitative research design incorporating both group and individual interviews was the most appropriate approach to take, the literature on interviewing children was also reviewed. The most salient features of that literature, which further informed the research design, are discussed below.

3.3.3 Interviewing Children

There are a number of issues to consider when planning research with children. For example, it has been noted that children are not able to concentrate for the same length of time as adults and that they may quickly become bored with a purely verbal interview (Hill *et al.*, 1996; Bushin, 2007). Additionally, although there is arguably an unequal power balance between the researcher and their adult participants, it is widely acknowledged that this power imbalance is more pronounced in research with children. This imbalance may lead to children responding in a way they believe the researcher wants or feeling uneasy during the interview (Hill *et al.*, 1996; Ireland and Holloway, 1996; Clark, 1999; Harden *et al.*, 2000; Punch, 2002b; Robinson and Kellett, 2004; Bushin, 2007; Cook and Hess, 2007).

It has been found that using age appropriate tasks with children can help to overcome these problems. Firstly, giving children tasks can help to engage their interest and keep them focused so they do not get bored (Hill *et al.*, 1996; Punch, 2002a; Harden *et al.*, 2010). Tasks can also be memory probing and act as a stimulus for talk (Harden *et al.*, 2000; Punch, 2002a). Additionally, it has been argued that tasks can lessen the asymmetrical power relationship between the adult researcher and child participant by helping to build rapport, relax the child and put the child in control (Harden *et al.*, 2000, 2010; Punch, 2002b).

It has also been noted that analysing the responses to tasks children have been given may not be the most appropriate way to access children's views because the researcher may misinterpret what the children have produced (Harden *et al.*, 2000). To overcome this, Morrow and Richards (1996) argue that it is important for children to interpret their own data (their written or illustrative responses to tasks, not their speech). Similarly, Punch (2002a, 2002b), Harden *et al.* (2000) and Hill *et al.* (1996) believe that the most fruitful data are produced when combining tasks with more traditional interview techniques.

Based on the above discussion, an activity was included in the interviews involving children. It was decided that tasks and interviews would be combined in order to engage the children, provide a stimulus for talk and allow the children to describe what they produced. It was also hoped that using tasks would ease rapport between the researcher and the children. There are a number of tasks that have been utilised in research with children; however, children's varying interests and competencies need to be taken into account when designing research, as not all techniques are suitable for all children (Cahill, 2007). A number of tasks involve children reading or writing and therefore require a certain level of literacy skills (Hill *et al.*, 1996). As was noted in the Chapter One, children with epilepsy are more likely than children in the general population to experience learning difficulties. Consequently, tasks involving literacy skills were kept to a

minimum. It was decided that autodriver photo-elicitation interviews would be conducted with the children in this study (more details are given in subsection 3.3.6) and that the group interviews would be based around a task for the whole family, which is the focus of the following subsection.

3.3.4 Task-Based Group Interviews

During the group interviews the family members were asked to carry out a task together for two reasons. Firstly, based on the above discussion, the task was intended to engage and focus the children. Secondly, O’Kane (2002) argues that making a group interview participatory encourages dialogue between the participants. The families were asked to make a plan of all their activities and interactions on a typical weekday and a typical weekend day, and they could decide if they wanted to make these plans individually or together. It was intended that the plans would give the researcher an insight into the families’ routines and highlight significant aspects of their relationships with one another, e.g. who was dependent on who and for what and who spent the most time together.

The researcher began the group interviews by showing each family her own plan of a typical weekday and weekend day. It was hoped that this would relax the participants and allow them to get to know her. Participants were then provided with coloured pens and A3 pieces of paper. The participants could decide whether to draw and/or write; by allowing both methods everyone could be involved if they wished. Additionally, if some participants preferred not to draw or write they could still be included in the discussion about what to include in the plans. These plans were not analysed but were used purely as a way to engage the participants and encourage them to interact with one another.

An interview guide (see Appendix 1) was used to probe some of the details of the participants’ daily routines. In particular, the times family members spent together and what they did during those times were

explored. For example, routines around mealtimes, such as where people ate, when and with whom, were discussed. Additionally, morning and bedtime routines as well as hobbies or activities that family members participated in together were explored. Moreover, although the participants knew that epilepsy was the focus of the research, the condition was only discussed if family members introduced the topic when describing a typical day. This decision was made so as not to make any family member feel uncomfortable about what they felt was appropriate to say in front of other family members, and so the child with epilepsy did not feel all the attention was on them. Reflections on the group interviews are given in section 3.6.1, but next the in-depth semi-structured interviews with parents are outlined.

3.3.5 In-Depth Semi-Structured Interviews with Parents

In-depth semi-structured interviews are the primary way in which adults' personal relationships have been researched (Gabb, 2008), and it was consequently decided that this method was most appropriate for interviewing the parents. The parents' interviews were guided using an interview schedule (see Appendix 2), in order to give some structure to the conversation (Rapley, 2004). It was also hoped that the introduction of similar topics would allow for comparisons to be made between the participants' responses. The interview schedule included: the history of their child's epilepsy (i.e. type of seizures, first seizure, diagnosis and the different medications/treatments used), parents' interactions with different family members, their view of sibling relationships, food and mealtimes in their family, how they felt having a child with epilepsy had impacted on their family life and whether they felt epilepsy was a stigmatised condition. In the families using the ketogenic diet, food and mealtimes were covered in much greater depth. For instance, the child's daily food consumption, parents' daily routine in relation to implementing the diet, the child's food preferences, preparation time, cost, managing the diet on special occasions, difficulties associated with implementing the diet, how they fitted the diet into their daily lives and others' reactions to the diet were all covered.

The third type of interview that the researcher intended to conduct was autodriven photo-elicitation interviews with the children with epilepsy and their siblings, which are described below.

3.3.6 Autodriven Photo-Elicitation Interviews with Children

An autodriven interview refers to an interview where the participant produces material that they then comment on (Clark, 1999), while photo-elicitation refers to photographs being used as the stimulus for discussion (Harper, 2010). It was thought that autodriven photo-elicitation interviews would be appropriate for a number of reasons. Firstly, this approach had been successfully used with preschool children through to those who were 17 years old (Cook and Hess, 2007; Croghan *et al.*, 2008). Furthermore, this technique also proved successful when employed with children with learning difficulties (Cook and Hess, 2007; Carpenter and McConkey, 2012). Therefore, it was thought that photo-elicitation would be suitable for the varying capabilities and interests of children, ensuring that as many children as possible could take part.

Photographs can give an insight into participants' everyday lives, routines and relationships (Holland *et al.*, 2010). Additionally, Clark-Ibáñez believes that 'photographs elicit extended personal narratives that illuminate the viewers' lives and experiences' (2004: 1151). Furthermore, it has been argued that children find it easier to talk about topics when they have a visual prompt, rather than discussing abstract issues (Zartler and Richter, 2014). Children have also been found to give more elaborate responses when they have photographs to refer to (Cappello, 2005). In addition, children have been found to raise sensitive topics in photo-elicitation interviews (Clark, 1999; Zartler and Richter, 2014), sometimes covering topics that had not been brought up in exclusively verbal interviews (Croghan *et al.*, 2008). Therefore, it was hoped that a combination of the photographs and children's comments would give an

insight into their lived experiences in more depth than would have been expected from purely verbal interviews.

At the end of the group interview this researcher gave each child a disposable single-use camera. Many researchers who have conducted photo-elicitation interviews with children have used single-use cameras (Clark, 1999; Baker and Weller, 2003; Sharples *et al.*, 2003; Clark-Ibáñez, 2004; Cappello, 2005; Croghan *et al.*, 2008; Zartler and Richter, 2014) and it was thought that this type of camera would be simple to use. Furthermore, it was not financially possible to provide children with digital cameras.

When the children were given their cameras they were also given an instruction sheet (see Appendix 3). The researcher talked through the instruction sheet and explained what she wanted the children to do and how to use the cameras. The researcher also helped the children to label their cameras so that they could tell them apart. The children were asked firstly to write their name on a large piece of paper and take a photo of it or to ask someone else to take a photo of them; this was so that the researcher knew which set of photos belonged to which child when they were developed (Baker and Weller, 2003). It was then explained to the children that over the course of approximately one week they were to take photos on four topics: (i) Who I live with, (ii) What I like to do with my family, (iii) Food and meal times in my family and (iv) What epilepsy means to me. The cameras were left with the children so they were free to take photographs of their choice (Sharples *et al.*, 2003; Cappello, 2005). The researcher either arranged to collect the cameras when she returned to conduct the parent's interview or parents were given a stamped and addressed padded envelope to return the cameras to the researcher when the children had finished taking their photographs.

During the interviews, the children were asked to talk about their photos and as they sorted through the photographs the researcher asked questions about the people and activities that the children introduced. As

well as using the photographs as a stimulus for talk, the researcher also used an interview schedule to ensure that similar topics were covered in each interview (see Appendix 4). For example, all children were asked about their relationship with each family member, who they ate with and where, their/their sibling's medications, their experience of seizures, whether they thought anyone treated themselves/their sibling differently because of their epilepsy and what impact they felt their/their sibling's epilepsy had had on their life. Epilepsy was one of the last topics to be covered, if the children did not introduce it with their photos sooner, because it was thought that this was likely to be the most sensitive topic and introducing it towards the end of the interview gave the child time to feel comfortable talking to the researcher. At the end of each child's interview they were given a set of the photographs they took as a thank you for taking part in the research (Clark, 1999; Baker and Weller, 2003; Croghan *et al.*, 2008).

Now that the different types of interviews have been discussed, the final subsection addresses the procedural considerations that were made when planning the research.

3.3.7 Procedural Considerations

Many researchers have noted that the characteristics of the interviewer can impact on the research process (Finch, 1993; Fontana and Frey, 2000; Byrne, 2004; Seidman, 2006). Those eligible to participate in this study could have been of any: ethnic group, socioeconomic class or gender, and there was going to be a large variation in the ages of the participants as the sample included children and adults. Consequently, it was not possible to select an interviewer most suited to the characteristics of the sample. It was also not possible to select an interviewer who would best match the characteristics of the sample because this research was for a PhD, and was thus conducted by the student.

The parents were asked to choose a time and location that was convenient for the interviews to be conducted. It was expected that most of the interviews would be carried out in the participants' own homes. Creswell (2003) argues that this is beneficial because it is a natural setting where the participant feels comfortable. The home environment has also been cited as an appropriate space in which to interview children because children may feel more comfortable in familiar surroundings (Ireland and Holloway, 1996; Harden *et al.*, 2010) and may also be more used to being listened to in their own homes (Bushin, 2007).

All interviews were recorded using two audio recording devices and then transcribed. Recording the interviews was intended to speed up the process of interviewing, as the researcher did not have to take extensive notes during the interviews (Rapley, 2004). It also meant that the researcher could give the participants her full attention, and could therefore concentrate to ensure that, as far as possible, all the appropriate questions were asked. Additionally, recording the interviews meant that there was an accurate record of what had been said, which meant that the analysis did not rely on the researcher's memory. Each audio recording device was positioned differently so that if there was any interference on one recording, the other recording could be used.

This section has detailed the research design for this study. Attention now shifts to the ethical considerations that were made when planning the research.

3.4 Ethical Considerations

Drawing on the British Sociological Association's (2002) Statement of Ethical Practice and the Social Research Association's (2003) Ethical Guidelines, the primary ethical considerations that were made when planning and conducting the research centred on: gaining informed consent from the participants, particularly children who are classed as a vulnerable

group; avoiding adverse social or psychological effects as a result of participation; issues of child protection and the potential for a disclosure of child abuse; anonymity and confidentiality; and minimising the risk of harm to the researcher. The ways in which these issues were dealt with are discussed below. Furthermore, prior to commencing recruitment and data collection, ethical approval was granted from the Centre for Criminology and Sociology's ethics committee at Royal Holloway, University of London.

The research was advertised through a number of charities (further details on the recruitment process are given in section 3.5). It was anticipated that it would be parents who would read the adverts. If they were interested in taking part they were asked to contact the researcher directly (using the details provided at the end of each advert) who then provided them with further information. When parents made contact they were posted an information sheet detailing what the research would involve, the research aims and their rights should they choose to participate. It was hoped that the researcher would be able to interview children in families using the ketogenic diet, but this was not possible (which is discussed further in section 3.5). As a result, two different information sheets were used – one for parents of children using only medications (see Appendix 5) and another for parents implementing the ketogenic diet (see Appendix 6). Parents of children using only medications were also asked for the names of their children who would be involved in the research and an age appropriate information leaflet (see Appendix 7) was sent to each child. In only one instance did a parent say she did not want to give her children's names and the children's leaflets were instead included with the parent's information sheet. The children's leaflets also detailed the aims of the research, their rights if they chose to participate and what their individual participation would involve. It was hoped that sending the children separate leaflets would emphasise that it was also the child's choice regarding whether they would like to participate. If parents did not reply after being sent the information they were followed up once.

A number of researchers have found it beneficial to involve children when designing their information leaflets to ensure that they are suitable (Cree *et al.*, 2002; Baker and Weller, 2003; Alderson, 2004; Alderson and Morrow, 2004; Lundy and McEvoy, 2012). Consequently, prior to recruitment, *Epilepsy Action* sent the information sheet for families using medications, the children's information leaflet and the photo-elicitation instruction sheet to a group of 6 parents who had a child with epilepsy, some of whom had a research background. These parents then gave feedback on the information provided, if they felt anything was missing and whether they thought the children's information was age appropriate. A number of these parents also consulted their children. The feedback was overwhelmingly positive, with all respondents saying that they thought families would want to take part and that the information was easy to understand. However, one respondent commented on the phrasing of the promise of confidentiality on the child's leaflet, noting that if a child disclosed that they were being abused then the researcher would have to pass that information on. As a result of this feedback the wording on the child's leaflet was adjusted with the new version stating that the researcher would not inform other family members about what had been said during their interviews.

Participants were asked to give their informed consent at the beginning of the research process. Participants had to sign to say that they understood what their participation would involve, that they could withdraw at any time and that they could refuse to answer any questions or ask for the recording equipment to be switched off, in line with best practice (Fontana and Frey, 2000; Ali and Kelly, 2004; Byrne, 2004; Ryen, 2004) (see Appendix 8 for the consent form used for parents implementing the ketogenic diet). Parents in families using only medications were also asked to consent to their children being interviewed and to photographs being taken of themselves, of their family members and in their homes (see Appendix 9). Additionally, drawing on previous research with children (Ireland and Holloway, 1996; Morrow and Richards, 1996; Cree *et al.*, 2002;

Morris, 2003; Alderson and Morrow, 2004; Kellett and Ding, 2004; Bushin, 2007), children's consent was also sought regarding their participation and to photographs being taken of themselves and in their homes (see Appendix 10). Furthermore, at the beginning of each interview the researcher checked with each participant that they were happy to continue with their involvement in the research and reminded them of their rights.

It is acknowledged that gaining consent from children can be problematic as they are a vulnerable group. However, the researcher attempted to ensure that the children were fully informed and happy to be involved in the research in the following ways. Firstly, the children were provided with an age appropriate information leaflet prior to their parent arranging a time for the first stage of the research, meaning they were informed about what the research would involve prior to taking part (Hill *et al.*, 1996; Ireland and Holloway, 1996; Mahon *et al.*, 1996; Punch, 2002a; Bushin, 2007; Harden *et al.*, 2010; Holland *et al.*, 2010). Providing children with this leaflet gave them the opportunity to communicate any reservations they had about participating to their parents. Indeed, one parent who had enquired about the research said her daughter had told her that she did not want to take photos; the parent was then able to opt out of the research on behalf of the child without the child feeling pressurised by the researcher. The children were also asked at the beginning of each interview if they were happy to participate, giving them the opportunity to say for themselves if they did not want to take part. Additionally, at the beginning of each interview, the researcher referred back to the children's information leaflet and reminded them that they did not have to answer any questions that they did not want to and that they could stop the interview at any time. The children were also given the opportunity at the beginning of each interview to ask the researcher questions in case there was anything they were unsure of.

Interview recordings and transcripts were kept confidential, as they were stored in a locked filing cabinet separate from the participant

identifier code (Ali and Kelly, 2004). Participants' anonymity has also been maintained in the write up of the research as individual participants have been referred to using pseudonyms so they cannot be identified (Byrne, 2004).

As confidentiality was ensured to all participants, the researcher did not disclose to any family member what another had said (Bushin, 2007; Warin *et al.*, 2007; Zartler, 2010). The participants were therefore able to decide what they told other family members about what they disclosed in their interviews. Due to the nature of family life, the researcher was not able to guarantee the children that no one would see their photographs, but the children were assured that the researcher would not share their photographs with any of their family members. The one exception to confidentiality would have been if a child disclosed that they were at risk, in which case the researcher would have had to pass that information on to an appropriate party in order to protect the child (Mahon *et al.*, 1996; Morrow and Richards, 1996; Alderson and Morrow, 2004; France, 2004). The researcher also obtained a clear Criminal Records Bureau check prior to commencing the research, which parents were informed of and could ask to see (Alderson, 2004; France, 2004).

As was mentioned in subsection 3.3.3, it has been argued that there are unequal power relations inherent in interviews. It is claimed that the interviewer is the person with the power and that participants may feel under pressure to participate or answer questions they do not feel comfortable answering (Seidman, 2006). It has also been argued that this asymmetrical power relationship is even more pertinent during interviews with children (Hill *et al.*, 1996; Ireland and Holloway, 1996; Clark, 1999; Harden *et al.*, 2000; Punch, 2002b; Bushin, 2007; Cook and Hess, 2007). However, in this piece of research parents had responded to adverts indicating that they were willing to tell their stories. Parents and children were also reminded before the interviews that they did not have to answer any questions. Additionally, the inclusion of photo-elicitation interviews

with the children was intended to reduce the unequal power relationship between the adult researcher and child participant. Indeed, it has been argued that engaging with the photographs puts the child at ease and they can choose what photographs they take and how much they wish to disclose about each one (Clark, 1999; Clark-Ibáñez, 2004; Cappello, 2005; Croghan *et al.*, 2008; Zartler and Richter, 2014).

As some of the topics covered in the interviews were of a sensitive nature, such as symptoms and onset of the condition, emergency hospital admissions and personal relationships, *Epilepsy Action* agreed that participants could be directed to them if they felt they needed any emotional support. Furthermore, if parents or children became upset they were given the opportunity to take a break, reminded that they could end the interview and the researcher also managed each situation as it arose and decided whether to change the subject of the conversation.

Also in accordance with the ethical approval that was granted, each family will be sent a brief summary of the research findings when analysis is complete and the research has been written up.

Furthermore, as the researcher was alone with participants during the interviews, in order to minimise risk to her, a close friend or relative was always informed about where she was. The researcher also carried a mobile phone with her at all times when visiting families and informed a friend or relative when she entered and left participants' homes.

In this chapter, so far, the design of the research in relation to methodology and ethics has been outlined. Next, an account of the recruitment process and a description of the participants are provided.

3.5 The Recruitment Process and Participants

It was decided that participants would be recruited through charities because, as the research was qualitative in nature, only a relatively small sample was needed. The research was advertised through a number of charities between November 2012 and October 2013. Originally, one advert asked for families with two children aged 7-14 years, with one of those children being treated for epilepsy with medications (see Appendix 11); and a second advert again asked for families with two children aged 7-14, but with one of those children being treated with the ketogenic diet (see Appendix 12). However, due to difficulties recruiting participants, the inclusion criteria for the research was modified (which will be explained in more detail later on in this section) and a third advert just recruiting parents of children on the diet was used (see Appendix 13).

Being sponsored by and thus having a contact at *Epilepsy Action* proved extremely helpful with regard to recruitment: the contact organised for adverts to be placed on the charity's website (see Appendix 11, 12 and 13); the research was advertised twice in the charity's magazine (see Appendix 14 and 15); details were sent to local support groups (see Appendix 16); two adverts asking for families using medications were posted on Facebook and Twitter (see Appendix 17) and a further Facebook and Twitter advert asking for families using the ketogenic diet was also posted (see Appendix 18). Furthermore, when two other charities did not respond, the researcher's contact was able to arrange for these charities to advertise also. *Epilepsy Research UK* advertised in their online newsletter (see Appendix 19); *Epilepsy Parents* and *ESUK* allowed the researcher to place adverts on their Facebook pages (see Appendix 20); *The Daisy Garland*, which supports families using the ketogenic diet, placed an advert on their website and also advertised for participants in their newsletter (see Appendix 21); and *Matthew's Friends*, which is also focused on the ketogenic diet, allowed the researcher to place two adverts on their forum (see Appendix 22). A slightly modified advert was also placed on the *Epilepsy*

Society forum in the ‘Parents’ section (see Appendix 23); the charity asked that information relating to Epilepsy Action be removed from the adverts before being posted. In return for the help received, Epilepsy Action will be provided with a full report of the research findings and a 250-word summary suitable for a lay audience.

The original target number for families using medications was 10. In total 28 families contacted the researcher for further information and 14 of those families chose to take part. The researcher recruited families beyond the original target because it was not possible to interview all family members in every family (more details on the completed interviews are given in subsection 3.6.3).

The adverts asked for families with children aged between seven and 14 years. However, due to problems with recruitment this criterion was adjusted slightly. One family came forward whose child with epilepsy was aged five and they were included in the sample. Additionally, the siblings who participated were aged 6-16 years. Further details on the families using medications are given below in Table 3.1.

Table 3.1 – Participants in Families Using Medications

Family	Parent(s)	Child with Epilepsy	Child’s Age	Sibling	Sibling’s Age
1	Nicola and Steve	Zak	13	Chloe	6
2	Emma	Tom	9	Natasha	11
3	Sarah	Chris	11	Ellie	7
4	Samantha	Harry	8	Daniel	11
5	Marie and Robert	Chelsea	8	Joseph	7
6	Carol	Rosie	9	Zoe	16
7	Ruth	N/A	N/A	Gemma	7
8	Kate	Max	7	Amelia	13
9	Catherine	Molly	8	Elliott	8
10	Zara	Isaac	9	Nathan	11
11	Heather	Ross	10	N/A	N/A
12	Anita	Lydia	12	Natalie	14
13	Donna	Noah	5	Layla	8
14	Shannon	Dylan	9	Logan	7

The table illustrates that the sibling in Family 11 did not participate; this was because his mother felt he was too young. Furthermore, the child with epilepsy did not participate in Family 7 because of her severe learning difficulties.

As can be seen in Table 3.1, in the families using medications 14 mothers and two fathers participated. In these families, nine of the children with epilepsy were male and four were female; five of the siblings were male and eight were female; and seven of the siblings were older than the child with epilepsy, five were younger and two of the children were twins. Parents in 13 of the 14 families were also asked to complete a basic demographics questionnaire (see Appendix 24). Of the 15 parents for whom data is available, the majority self-identified as White British, one was Irish, one was from Continental Europe and one identified specifically as being Scottish. The families ranged in location from Yorkshire to Devon, and one had recently moved to Northern Ireland. These families were living in households that ranged in size from three to five people. The majority were two parent families, two of which were stepfamilies. Two families were single parent families and another had for a long time been a single parent family but had moved in with the mother's long-term partner a few months before the interviews. Three parents chose not to state their household income, but the majority had an income above the national median (based on one adult working full-time (Pike, 2011)); five were in the 3rd quartile, four were in the top quartile and only one family had an income below the national median.

Because only a small proportion of children with epilepsy are treated with the ketogenic diet and because these children have drug-resistant forms of epilepsy, which are often accompanied by severe learning difficulties, the original target for families using the ketogenic diet was only five. Achieving this target would have meant 15 family members participating in total (five parents, five children using the diet and five siblings). In total, 15 families using the diet came forward and, after

considering the information provided, 10 of those families chose to take part in the research. However, after initially trying to recruit families using the ketogenic diet where all family members could participate it became evident that this would not be possible. Instead, only parents were recruited and it was hoped that after interviewing the parents it might be possible to access some of the children and their siblings. However, only one sibling ended up taking part in the study. Parents acted as gate keepers and most felt that their children would not be able to take part because of their learning difficulties. Additionally, one parent said she would rather her son did not take part because she did not want him to feel the diet drew attention to him. More details of these families are given in Table 3.2.

Table 3.2 – Families Using Dietary Treatment

Keto Family	Participants	Child on the Diet	Child's Age	Diet Type	Location	Ethnicity
1	Alison and Paul	Connor	6	Classical	UK	White British
2	Ana	Stefan	10	Classical	Eastern Europe	Eastern European
3	Ellen, Peter and Grace (Sibling – 11)	Faye	9	Classical	UK	White British
4	Hannah	Jack	5	MAD	Non-Mainland UK	White British
5	Hashani	Isuri	3	Classical	UK	Asain
6	Jane	Toby	7	MCT	UK	White British
7	Jessica	Lukas	6	Classical	Western Europe	White European
8	Kelly	Ryan	10	MCT	Non-Mainland UK	White British
9	Naomi	Maisie	5	Classical	UK	White British
10	Rachel	Daisy	5	Classical	UK	White British

As can be seen in the table, a number of the families did not live in mainland UK; it was consequently not possible to interview them face-to-

face, which meant the siblings were subsequently not interviewed. Additionally, one sibling chose not to take part and two parents said they would rather their children did not participate.

In total, 10 mothers and two fathers in families using the ketogenic diet took part in the research. Six of the children on the diet were male, four were female and they ranged in age from 3-10 years. Seven of the children were on the classical version of the diet, two were on the MCT diet and one was on the MAD. The one sibling who participated was female and 11 years old. Of the participants from the UK, all but one were white, with one parent being Asian (foreign-born). Of those living on the UK mainland, location ranged from North Yorkshire to Somerset. They were all two-parent households ranging in size from four to six people. One parent did not state their household income, but the majority had an income above the national average, with 2 in the 3rd quartile and six in the top quartile. One family had an income in the bottom quartile, but the parents were partners in a business and could be described as upper middle class.

In total, 24 families participated in this study, and from those families 28 parents, 13 children with epilepsy and 14 siblings took part. The methods used to collect the data from these participants are reflected upon in the next section.

3.6 Data Collection

In the families using only medications for treatment, firstly, a group interview with the child with epilepsy, their sibling and parent(s) was conducted (14 in total). Secondly, semi-structured in-depth interviews were carried out with one or both parents in 13 of the families. Thirdly, autodriver photo-elicitation interviews were conducted with the children with epilepsy (10 in total) and their siblings (10 in total). It was hoped that the same procedure could be followed in families using the ketogenic diet, but because it was only possible to recruit parents and one sibling, one in-

depth semi-structured interview was conducted in each family with those family members who agreed to take part (10 in total).

The research design using the three types of interviews, described in section 3.3, was initially piloted on one family who had helped to review the information materials through *Epilepsy Action*. The purpose of the piloting phase was so the researcher could evaluate the effectiveness of the methods chosen, gain feedback from the participants and adapt the interview schedules and/or procedure accordingly. As a result of this pilot study, more detailed questions were added to the children's interview guide because it was found that the children often gave quite short answers.

It was not possible to conduct all of the interviews face-to-face (further details of the interviews that were not conducted face-to-face are given in subsection 3.6.2). However, the majority of the face-to-face interviews were conducted in the participants' homes and only one was conducted in a café at the participant's request. The particular café that the participant chose was quiet and there were no other customers or staff present during the interview, which meant this still provided a private location for the interview to take place.

This section continues with reflections on the methods used. The remainder of this section is, therefore, split into three subsections focusing on the three types of interviews that were used (group interviews, in-depth semi-structured interviews with parents and autodriven photo-elicitation interviews with the children).

3.6.1 The Group Interviews

Five of the 14 families made their plans together and the other nine made individual plans. In two of the families that made individual plans, parents also made their own plans, but more commonly parents helped the children with writing or thinking about what to put in their plans. In one family that

chose to make a plan together none of the family members wanted to write, so the researcher wrote for them. Despite these varying approaches to the task, family members interacted with one another to the same extent and spoke in the same level of detail about their daily routines. On the whole the children were engaged in the task and there was only one family where the children seemed disinterested and the interview ended rather quickly.

The group interviews lasted between 12 minutes and an hour, with nine of the 14 being roughly 30 minutes in length. On reflection, very little came out of the group interviews that was not spoken about in the individual interviews. However, the plans did give the researcher an insight into which children were comfortable discussing their condition, as those who did not include their medication in their plans, or did not bring up their epilepsy, were children who seemed uneasy talking about their condition or tried to avoid the topic. Overall, the group interviews were most useful in allowing the children time to get to know the researcher before their individual interviews; although not all the children were shy, those who were tended to relax as the interview went on and appeared less shy when the researcher returned to conduct their individual interviews.

The next stage of the research in families using medications was the parents' interviews. Seven of these interviews took place on the same day as the group interview and the remaining six were conducted between one and seven weeks after the group interview (four were carried out within 10 days of the group interview). The parents' interviews are the focus of the next subsection, and this includes an overview of all the interviews that were conducted in families using the ketogenic diet.

3.6.2 The Parents' Interviews

It had been intended that only one parent would be interviewed in each family and that these would be individual interviews, but in four of the families both parents were present and expecting to be interviewed, so in

these instances both parents were interviewed as a couple. The presence of both parents did mean that there were sometimes disagreements between them, but this provided an insight into the perspective of both parents. In one of these families (Keto Family 3) the sibling also participated. In five other families one or both children were present and occasionally joined in; although one of these parents asked her daughter to play in another room when the topic of SUDEP arose. It is not possible to know for certain how the children's presence shaped the data, but the context of each interview was considered when the data were analysed.

The parents' interviews lasted between half an hour and two hours, with 14 of the 23 interviews being roughly one hour in length. Furthermore, parents gave very detailed answers and often used stories to illustrate their points, which meant the data from these interviews were extremely rich.

Because four of the families using the ketogenic diet did not live on the UK mainland it was not possible to conduct their interviews face-to-face. Table 3.3 summarises how the interviews in each of the families using the ketogenic diet were conducted.

Table 3.3 Interviews in Families Using Dietary Treatment

Keto Family	Type of Interview
1	Face-to-Face
2	Email
3	Face-to-Face
4	Phone
5	Face-to-Face
6	Face-to-Face
7	Skype
8	Phone
9	Face-to-Face
10	Face-to-Face

On reflection, the interview that was conducted via email was limited because the interviewer was not able to probe the participant's answers, but the responses she gave to the questions were very detailed. Additionally, one limitation of the phone and Skype (without video) interviews was that

the researcher was unable to use non-verbal cues and, therefore, at times it was difficult to know whether the participant had finished speaking or whether they were pausing to think. However, when comparing the data, no disparity existed in terms of the depth of response between the interviews conducted in person and those conducted using alternative means.

This subsection has focused on the parents' interviews; the next considers the children's autodriven photo-elicitation interviews.

3.6.3 The Children's Interviews

Unfortunately there was some attrition and it was not possible to interview the children in every family. Table 3.4 illustrates which interviews were completed.

Table 3.4 Completed Interviews in Families Using Medications

Family	Group Interview	Parent Interview	Child's Interview	Sibling's Interview
1	√	√	√	√
2	√	√	√	√
3	√	√	√	√
4	√	√	√	√
5	√	√		
6	√	√	√	√
7	√	√		√
8	√	√		
9	√	√	√	√
10	√	√	√	
11	√	√	√	√
12	√	√	√	√
13	√	√	√	√
14	√			

As was mentioned in section 3.5, the sibling in Family 10 did not take part because his mum felt he was too young and the child with epilepsy in Family 7 had severe learning difficulties and was also not able to participate. As can be seen in the table, three families dropped out of the study before the children's interviews could be conducted, and one of these was before the

parent's interview was carried out as well. Although not all the interviews were completed in these three families, the data that were collected were analysed and extracts are included in the empirical chapters of this thesis.

Although 20 children were interviewed, in two families the child with epilepsy and their sibling were interviewed together, and their parent was also present. In one family this was because the child with epilepsy had learning difficulties and having other family members present helped with regard to interpreting her responses and encouraging her to answer questions; and in the other family both children were quite shy and seemed happier to have each other and their mum present. Additionally, one parent chose to be present in both her children's interviews. In another family the sibling was particularly shy and wanted her mum to be present, but she relaxed during the interview and actually sent her mum away to fetch things that she wanted to show the researcher. It is acknowledged that having other family members present can shape the data, and this was given consideration when conducting the analysis. However, it was felt that making children as comfortable as possible during the interviews was a priority.

One of the children's interviews was conducted on the same day as the group interview (due to the family's location it was not possible to make multiple visits) and the rest were carried out between eight days and two months after the group interviews. These interviews lasted between five and 35 minutes, with eight of the 18 interviews being roughly 20 minutes in length.

The results of using single-use cameras were mixed. Some of the children's photos came out well, but there were many photos taken without the flash on, which meant it was not possible to see what the children had photographed. Furthermore, although it was thought that this type of camera would be simple for the children to use, due to the widespread use of digital cameras and the age of the children in this study, many,

particularly the younger ones, found these cameras somewhat confusing. The children were not used to having to hold the camera to their face, turn the flash on or having a limited number of photos they could take. Furthermore, some of the children were also confused as to why they could not review their photos after taking them. However, this did make the cameras somewhat of a novelty and because the children had not been able to view their photos prior to the interviews they were often excited to see how they had come out.

Photo-elicitation proved to be a useful technique with many of the children. They were creative with the photos they took and found ways to visually represent what epilepsy meant to them. For example, children took photos of medications, protective helmets, identification bracelets and charity wristbands. Additionally, some of the children also took photos of objects that, from an outsider's perspective, did not appear to be associated with epilepsy; however, when the children spoke about their photos it was clear that they did relate to their condition. For instance, two children took photos of snacks because hunger was a trigger for their seizures and one child took a photo of his bed because the sleeping arrangements in his household were adjusted when he was diagnosed. Furthermore, some children took photos of comments they had written or faces they had drawn to express the emotions they associated with their condition. Photo-elicitation, therefore, was helpful because it gave a clear indication of what aspects of the condition were significant to the children.

However, with a minority of the children photo-elicitation was not a successful way of accessing their epilepsy experiences. All the children were asked to take at least one photo related to epilepsy. However, one child with epilepsy and one sibling took no photos in relation to the condition and on another child's camera the only photo relating to his epilepsy was a picture of his medication, and it is thought his mother took this photo. On reflection, the children not taking photos related to epilepsy was possibly a sign of informed dissent and their way of avoiding talking about the condition.

Bourke and Loveridge describe informed dissent as ‘the capacity and opportunity to ‘say or *express* no” (2014: 152 emphasis added). During these three children’s interviews it became apparent that they were not comfortable discussing the condition and they displayed informed dissent through verbal avoidance tactics and changes in their body language. For instance, children would change the topic, respond to questions with one-word answers or say ‘don’t know’ to every question. Furthermore, a change from open to closed body language was also seen to be an indicator of dissent. Although the children had been told they could stop the interview or choose not to answer questions they did not do this; it was therefore the researcher’s responsibility to interpret their responses and take the ethical decision to end the interviews.

Now that the data collection process has been discussed, the way in which the data were analysed is described.

3.7 Analysis

The researcher transcribed all the interviews *verbatim*, with the exception of the email interview. Although this was time-consuming it meant the researcher became familiar with the data (Fielding and Thomas, 2008). Transcribing *verbatim* also ensured that no data were lost at the early stages, which may have proved to be relevant later on.

The analysis process was aided through the use of NVivo 10 and the data were continually collected and analysed using a constructivist grounded theory approach (Charmaz, 2006). In contrast to Glaser and Strauss’ (1999) grounded theory method, a literature review was conducted prior to carrying out the interviews in order to gain an understanding of previous research on similar topics. But, in accordance with Glaser and Strauss’ (1999) grounded theory approach, rather than conducting the analysis after the final interview, the researcher transcribed and began the analysis after the very first interview, and continued in this way throughout

the data collection process. This approach allowed the researcher to begin to develop themes, which were explored further in subsequent interviews.

A constructivist grounded theory approach was chosen over other methods of analysis, such as a thematic analysis, because grounded theory allowed the researcher to collect data and conduct analysis at the same time. Simultaneously collecting and analysing the data had the advantage that the researcher was able to purposefully generate data that filled gaps in the emerging theories, rather than conducting the analysis when the entire data collection phase was complete. Additionally, this method of analysis meant that the constructed theories and concepts were grounded in the data, rather than being based on preconceived ideas (Glaser and Strauss, 1999; Charmaz, 2006). Furthermore, a constructivist grounded theory approach was adopted over classical grounded theory because the constructivist version is underpinned by the belief that data *and* theories are constructed. From this standpoint, data are jointly constructed by the participant and researcher, and the theory that results from the analysis is an '*interpretive* portrayal of the social world, not an exact picture of it' (Charmaz, 2006: 10 original emphasis).

The researcher began coding the data by looking for trends and patterns in what had been said as well as instances that did not fit these patterns, using the constant comparative method (Glaser and Strauss, 1999; Charmaz, 2006). Codes were developed from the meanings in the participants' speech (a full list of the codes used is given in Appendix 25) and the researcher wrote memos describing her thoughts on the developed categories and how they related to each other. Importantly, in order to conform to the constructivist approach, Charmaz (2006) argues that data should be treated as action when coding in order to acknowledge the data as constructs rather than facts. Through the process of coding and memo writing, gaps in the developing theories emerged and the researcher was able to purposefully collect data to fill these gaps. For example, it became evident that siblings significantly contributed to their brother or sister's

care and this was explored in more detail in the latter interviews in order to distinguish between the different roles siblings took on. Using the constant comparative method, the codes that were used initially described the different caring tasks that siblings took on, but later these were collapsed into categories that specified the different roles as theory regarding these roles developed. Data collection continued until categories became 'saturated' and no new theoretical insights were gleaned from subsequent data (Glaser and Strauss, 1999; Charmaz, 2006).

When conducting multiple perspective research, the researcher has a number of options regarding how to analyse the data (Perlesz and Lindsay, 2003; Ribbens-McCarthy *et al.*, 2003; Power, 2004; Zartler, 2010). Firstly, the accounts of individual family members can be analysed with the aim of identifying agreements and contradictions in their accounts; secondly, an overall story of each family can be built up and compared to the accounts of other families; or thirdly, the researcher can conduct a standpoint analysis from different groups' perspectives, i.e. parents, children with epilepsy and siblings (Ribbens-McCarthy *et al.*, 2003). Alternatively, the researcher can conduct a dyadic-analysis, focusing on each dyadic relationship in turn (Zartler, 2010).

It was considered that a standpoint analysis, from the varying perspectives of parents, children with epilepsy and siblings, was most beneficial in order to assess how different family members viewed and managed the condition. This type of analysis also highlighted similarities and differences between the viewpoints of different family members within the same family. Yet, when looking at the impact that having a child with epilepsy had on family relationships it was seen to be more beneficial to compare between the same dyadic relationships in different families. Therefore, the multiple perspective approach allowed the analysis to be tailored depending on the research question that was being addressed.

It has been noted that apparently contradictory data are common in multiple perspective research (Sands and Roer-Strier, 2006). However, it is argued that it is possible to make sense of dissonant data by considering the social conditions under which the varying pieces of data were produced (Perlesz and Lindsay, 2003; Power, 2004). Thus, a constructivist grounded theory approach that treats data as action (Charmaz, 2006) fits well with multiple perspective research because it acknowledges that data are constructs rather than facts. Indeed, when analysing the data from this study, the context of the interviews was given consideration and differing viewpoints are highlighted in the empirical chapters that follow. But next, the constraints on the research are considered.

3.8 Constraints on the Research

The four main constraints faced when conducting this piece of research were: that this was an inherited project, the recruitment process, extensive contact with families and the practicalities of interviewing children. These four areas are consequently the focus of this section.

The focus and research design for this study had been outlined prior to the student starting work on the project, as the funding for the research was from an Economic and Social Research Council collaborative studentship in conjunction with *Epilepsy Action*. This meant that certain topics, such as family relationships and the ketogenic diet, were included in the interview schedules and that some of the aspects of the research design had been decided on. However, the student was able to develop the interview schedules, set the topics for the children's photo-elicitation task and adapt the research design to include group interviews. Furthermore, using constructivist grounded theory meant that once data collection had begun, it was the data that had been collected that shaped the direction of the study.

The way in which the participants were recruited meant that a number of families who would have been eligible to participate were not contacted because they did not use the services of any of the charities. Furthermore, the majority of the families in the sample could be defined as middle class based on financial information from each household. Although not having a representative sample means that the findings are not generalisable to every family who has a child with epilepsy from a statistical representational viewpoint, because theoretical saturation was reached it can be argued that the findings are generalisable on theoretical grounds (Mitchell, 1983; Seale, 2004; Bryman, 2008). Thus, the findings presented within this thesis provide a detailed insight into family life in families with a child with epilepsy.

Furthermore, it had been hoped that it would be possible to interview children using the ketogenic diet and their siblings. Although it was acknowledged prior to recruitment that accessing children using the diet might be difficult, it was not anticipated that it would be as difficult as it subsequently turned out to be. Because so few children are treated with the diet, and because it is so labour intensive, it proved extremely difficult just to recruit parents. Indeed, parents in almost half of the families that took part were not living in mainland UK. As a result of these parents' location, it was not possible to interview them face-to-face, which meant it was also not possible to interview their children. Additionally, the majority of the children using the diet had severe learning difficulties and their parents felt they would not be able to take part in the research.

The extensive contact with families that was required to complete all three types of interview may have put some families off taking part. Indeed, three of the families that did agree to take part did not complete all the interviews and in a minority of the families, regrettably, there was a large gap between the group interview and the children's interviews. The children often spoke in less detail when compared to their parents, and because when families dropped out it was the children's interviews that

were not completed, their data were lacking. Indeed, theoretical saturation was reached with regard to the parents' data much earlier on. On reflection, because little came out of the group interviews that was not discussed in the individual interviews, it may have been more beneficial to limit the research process to just the parent and children's interviews. Furthermore, as the criteria for taking part in the study were quite specific (two children in a particular age range and both children and a parent being willing to participate) this reduced level of participation might have meant more families would have been willing/able to take part.

With regard to interviewing the children, as was mentioned in subsection 3.6.3, some of the children did not talk much about their epilepsy because they were not comfortable discussing the condition (this will be explored further in Chapters Five and Six). However, when children were happy to talk about their epilepsy, it seemed that the researcher and children sometimes drew on different linguistic codes, which were difficult for the other party to understand. Some of the researcher's words or phrases were meaningless or caused confusion for the children. For instance, it became evident during one of the children's interviews that he did not know what a seizure was because he had only ever referred to his seizures as 'bad dreams' or 'nightmares'. Therefore, when he replied 'don't know', he was not avoiding answering the researchers' questions, but he was genuinely unable to answer because he did not understand what he was being asked. This illustrated that the researcher had to be continuously reflexive regarding her use of language.

Equally, the children sometimes used descriptive phrases that the researcher was unable to identify with. For example, children frequently used the word 'weird' to describe the taste of their medications and sensations during and after seizures. When they were asked what 'weird' meant they often replied 'it's just weird'. The experiences that children were describing were meaningful to them; however, as they had not experienced anything that they felt would be a reasonable comparison, and

because the researcher had not tasted their medications or experienced their seizures, it was not possible for the researcher to relate to what they were describing or gain a meaningful understanding of their experiences.

3.9 Conclusion

This chapter has detailed the methodological approach taken and the method of analysis that was utilised. The research questions to be addressed in this thesis are: How do children and their family members experience living with childhood epilepsy? How do families manage childhood epilepsy? To what extent is concealment used as a management strategy for childhood epilepsy in contemporary society? How do family members view medications for childhood epilepsy? How does implementing the ketogenic diet affect the meanings attached to foods? How does childhood epilepsy affect family relationships? And, to what extent do siblings contribute to informal care practices associated with their brother or sister's epilepsy? It has been argued that in order to fully answer these questions it was necessary to include children in this piece of research and that it was important to take a multiple perspective approach so that a rounded picture of family life could be provided. Furthermore, because of the nature of the research questions, a qualitative approach was taken.

The data that are presented in the subsequent empirical chapters consist of the views of 28 parents, 13 children with epilepsy and 14 siblings. In the 14 families using medications, group interviews (14 in total), in-depth semi-structured interviews with parents (13 in total) and autodriver photo-elicitation interviews with the children with epilepsy (10 in total) and their siblings (10 in total) were conducted. Additionally, 12 parents and one sibling from 10 families using the ketogenic diet also took part in one in-depth semi-structured interview in each family.

The method of analysis used was a constructivist grounded theory approach. The constant comparative method was utilised throughout and it

is the results of this analysis that are presented in the empirical chapters that follow; the first of which explores family members' experiences of uncertainty.

Chapter Four: Living with Uncertainty

4.1 Introduction

The focus of this chapter is family members' experiences of living with childhood epilepsy, including their discussions regarding onset, diagnosis, daily life with the condition and their thoughts about the future. Thus, the research question addressed in this chapter is: How do children with epilepsy and their family members experience living with childhood epilepsy? Uncertainty was a prevalent theme in participants' descriptions of the past, present and future, and is, therefore, the overarching concept drawn upon throughout this chapter. A further area of consideration is how family members responded to the uncertainties they described.

Uncertainty is a broad concept and some researchers have broken it down to distinguish between different types of uncertainty. For instance, Adamson (1997) talks about the difference between 'existential' and 'clinical' uncertainty. Furthermore, researchers focusing on the experience of chronic pain (Honkasalo, 2008), colitis (Kelly, 1992) and Parkinson's disease (Pinder, 1988) have all found symptomatic uncertainty relating to the timing of symptoms to be the most problematic form of uncertainty. Similarly, the findings relating to uncertainty in previous research on epilepsy primarily centre on the uncertainty associated with the timing of seizures (Schneider and Conrad, 1983; Scambler, 1989; Iphofen, 1990; Weinbren and Gill, 1998; Reis, 2001; Jacoby, 2002; Admi and Shaham, 2007). Additionally, there is the added uncertainty for some children with epilepsy and their parents as to whether the child will grow out of the condition (Schneider and Conrad, 1983). One aim for this chapter is to outline the different types of uncertainty in family members' comments in order to breakdown the concept of uncertainty specifically in relation to epilepsy during childhood. It is hoped that this exploration will provide a detailed and comprehensive overview of living with the condition.

A further type of clinical uncertainty discussed in the chronic illness literature is diagnostic uncertainty. It has been argued that diagnoses are valued because they provide an explanatory framework, legitimise illness and allow access to treatment (Jutel, 2009, 2011; Jutel and Nettleton, 2011). Consequently, diagnostic uncertainty can be problematic for individuals and can lead to ambivalence directed at the medical profession (Dumit, 2006; Nettleton, 2006). With regard to epilepsy there are no definitive diagnostic tests for the condition (Alarcón, 2012a) and there is a high rate of misdiagnosis (Bagshaw *et al.*, 2012b). However, only one sociological study on epilepsy includes a discussion of diagnostic uncertainty (Schneider and Conrad, 1983). Given the clinical uncertainty relating to diagnosis, it would be interesting to know whether diagnostic uncertainty forms a significant part of family members' experiences of childhood epilepsy.

Furthermore, although existential uncertainty has been explored from the perspective of people with a number of chronic conditions (for example, Kelly, 1992; Lillrank, 2003; Honkasalo, 2008; Brown and de Graaf, 2013) the experience of uncertainty by other family members has been somewhat neglected. Indeed, there is little research detailing if, and how, a person's condition can result in uncertainty for others (see Davis (1960) for an exception). Some researchers focusing on experiences of chronic conditions within the family mention feelings of uncertainty by family members but do not examine their experiences in detail (e.g. Waissman, 1990; Barton *et al.*, 2005; Richardson *et al.*, 2007). Scambler (1983) and Scambler and Hopkins (1988) found that adults with epilepsy spoke about how family members sometimes felt 'bewildered' or 'helpless' during their seizures, indicating that epilepsy can cause uncertainty for others. However, without asking family members themselves it is not possible to draw any direct conclusions. This chapter will address this gap by providing an examination of the way in which clinical uncertainty impacted on family members' experiences of uncertainty. It is intended that this insight will add to the current literature on the experience of chronic illness within the family.

Beyond experiences of uncertainty, the ways in which people manage uncertainties have also been an area of interest for many (Lillrank, 2003; Honkasalo, 2008; Zinn, 2008; Alaszewski and Coxon, 2009; Lee, 2010; Brown and de Graaf, 2013; Brown *et al.*, 2014). Zinn (2008) argues that people's responses to uncertainty fall on a continuum, with rational approaches at one end (such as risk assessments) and non-rational responses at the other (e.g. hope). The usefulness of distinguishing responses to uncertainty in terms of rationality will be evaluated within this chapter. Furthermore, in the existing literature on epilepsy, the primary way in which adults tried to manage uncertainty associated with the condition was by attempting to create certainty by producing theories as to why a seizure had occurred (Schneider and Conrad, 1983). It is intended that the analysis presented in this chapter will build on Schneider and Conrad's (1983) work by detailing the ways in which family members responded to different types of uncertainty.

This chapter begins with an exploration of family members' comments regarding past uncertainties relating to the onset of the condition and diagnosis. Next, the day-to-day uncertainties spoken about will be addressed. These related to three types of symptomatic uncertainty (the timing of seizures, the severity of symptoms and whether a seizure had occurred) and what is referred to as a 'cycle of uncertainty' where parents were not sure what changes in their child were related to the condition. Following on from this, there is a discussion on uncertain futures. Lastly, the four ways in which family members responded to uncertainty will be examined: reducing uncertainty, living in the present, hope and waiting.

4.2 Past Uncertainties

Children with epilepsy and their siblings did not speak at length about the onset of the condition when compared to their parents because the majority did not remember the initial occurrence of symptoms; however, parents detailed an uncertain time when symptoms presented themselves and they

began to think these behaviours were not 'normal'. The problems parents faced in relation to recognising symptoms is where this section begins. Following on from this, the focus shifts to how the process of diagnosis resulted in more uncertainty for many parents.

4.2.1 Recognising Symptoms

Parents in 13 of the 15 families where onset of the condition was spoken about in detail, described how they initially did not recognise the child's seizures as being 'a seizure' or cause for medical concern. Many of these parents explained that they had initially interpreted the child's symptoms by drawing on an understanding of childhood behaviour and concluded seizures were 'just one of those things children do'. For instance, many parents expressed the opinion that children sometimes do 'strange' things, daydream or play games, and this is what seizures tended to be interpreted as. Bury and Holme (1991) introduced the concept of the 'social clock', arguing that people have an idea of when in the life course certain conditions will occur. Based on parents' comments, the concept of the social clock can also be applied to explain how people originally interpret symptoms, therefore supporting Jutel's argument that 'a collective cultural position determines which symptoms we see, [and] which we brush off as insignificant' (2011: 61). Here parents drew on assumptions surrounding childhood behaviour in order to explain children's seizures, rather than positioning this behaviour in the medical domain.

In five of the 23 families it seemed that the child's seizures became part of ordinary daily life within the family. Although the children with epilepsy had little or no recollection of their first seizures (due to either their age at onset or the fact that they were unconscious during their seizures), similarly to the parents, siblings who could remember a time prior to diagnosis also explained that they had initially interpreted their brother or sister's seizures as 'normal' behaviour. For instance, when speaking about her sister's absence seizures, Natalie (14) explained 'I just thought

they [seizures] were like daydreams'. It seemed that siblings' perceptions regarding what was normal only changed when parents concluded that the child's symptoms were potentially a medical problem. However, parents did not always arrive at this conclusion quickly.

Indeed, parents began to pay closer attention when a behaviour continued or increased in frequency, leading to uncertainty regarding whether this behaviour was in fact 'normal'. For example, Emma spoke about not originally recognising her son's behaviour as a seizure.

Emma: He [Tom] started what is absences, but we didn't really know at the time. Just stopping, eye rolling a lot.

I: OK. And so you took him to the GP?

Emma: Yeah, not for a while though. I wanted to keep an eye on it and see if it wasn't just one of those things that kids do.

Emma's extract demonstrates that she was unsure about what her son was doing and why. This period of uncertainty is concurrent with the first stage of biographical disruption where bodily states are given more attention than usual; alternatively described by Bury as the "what is going on here' stage' (1982: 169). However, in contrast to Bury's (1982) work, here the onus was on parents, rather than the individual with the condition, to recognise symptoms and seek medical advice, illustrating that family members who are not presenting symptoms can also experience this phase of uncertainty.

However, even when parents had placed the child's behaviour in the medical sphere they could still not be sure what was happening. The uncertainty inherent in this experience was best summarised by Heather when she said 'we didn't know at first what was happening at all or what it was or why it was'. Parents passing through a stage of feeling unsure about what their child was doing and why was also found by Weinbren and Gill (1998) in their study of families with children with epilepsy; this phase of uncertainty is therefore likely to be a common experience for parents during the onset of childhood epilepsy.

Siblings who could recall onset of the condition also spoke about the phase of uncertainty that followed interpreting the child's seizures as normal. Therefore, similarly to the way in which all family members sometimes interpreted children's seizures as normal, rather than purely a parental experience, this phase of uncertainty may be a broader family experience. For instance, when asked how he feels now when his brother has a seizure, Nathan (11) said 'I'm quite calm because I know what's happening, but on the first time I was a bit worried because I was like 'what's happening?' So I was a bit confused'. Nathan clearly remembered questioning what his brother was doing and why, illustrating his uncertainty. However, when parents came to view children's behaviours as seizures this was explicitly passed on to siblings. As a result, siblings' uncertainty relating to their brother or sister's behaviour was resolved. However, gaining a diagnosis and resolving this uncertainty was not always simple due to diagnostic uncertainty, as we see below.

4.2.2 Diagnostic Uncertainty

Given the diagnostic uncertainty that is evident in the clinical literature, discussed in the introduction to this chapter, it is not surprising that prolonged uncertainty surrounding diagnosis featured in 11 of the 23 families' stories. Even in the other 12 families where a diagnosis was reached relatively quickly, there was often still a short period of uncertainty. This subsection begins with a discussion of parents' experiences of misdiagnosis and subsequently the process of reaching a diagnosis of epilepsy. Next, aspects of epilepsy, and particularly childhood epilepsy, that complicated the diagnostic process will be outlined. Finally, causal uncertainty that occurred after a diagnosis had been given will be explained.

Seven of the 23 children were said to have been misdiagnosed, according to the parents, and two of the children were reportedly misdiagnosed more than once. Parents recalled these children being incorrectly diagnosed as having an eye condition, vitamin B6 deficiency,

another vitamin deficiency, a nervous tick, and three were diagnosed with night terrors. Although not specific diagnoses, consultants also described children as 'a late developer' and 'attention seeking' when parents sought medical advice. These consultants' evaluations of the children's symptoms illustrate that it was not only parents, but also medical professionals, who used their social clock when interpreting children's symptoms. For instance, night terrors are only experienced by children, which explains why this diagnosis may have been given. Additionally, children being seen as 'a late developer' and as 'attention seeking' are likely to be linked to consultants' views on children and their stage in the life course.

Misdiagnosis was stressful for parents because uncertainties regarding the child's symptoms were renewed when the original diagnosis was deemed to be incorrect. Additionally, parents described losing faith in the ability of medical professionals to arrive at the right diagnosis. Similarly, it has been found that prolonged uncertainty among those with emergent illnesses (Dumit, 2006) and medically unexplained symptoms (Nettleton, 2006) can result in ambivalence towards the medical profession. Based on parents' statements it seems that the same loss of faith in the medical profession can be the result of misdiagnosis as well as prolonged uncertainty regarding diagnosis. Furthermore, as treatment often follows diagnosis (Jutel, 2009, 2011), parents also worried that their child had not received the appropriate treatment. For instance, Carol said that the medication her daughter was given for night terrors 'made it [Rosie's epilepsy] a hundred times worse'. Incidents like this led to parents feeling uncertain about the expertise of certain professionals.

In the 12 families where a diagnosis of epilepsy was reached relatively quickly parents were often told of other possible diagnoses. Almost all the children had MRI scans to look for brain abnormalities and one child was given a lumbar puncture to rule out the diagnosis of meningitis. Furthermore, some of the children's EEG results came back 'clear' and did not show any epileptic activity in the brain at the time of the

test. Consequently, the process surrounding diagnosis left many parents feeling uncertain. Below, Donna is describing her interaction with a consultant when she was not given a definitive answer regarding her son's diagnosis.

They said 'oh yeah, it looks like he [Noah] may have epilepsy'. I says 'what do you mean he 'may have'? He either has or he hasn't'. 'Oh no, but we think it is'. I says 'yeah, but you're a specialist, I've come here to get a diagnosis for my son, I don't want 'it may be' or 'possibly'. I want you to say 'yes, your son has this, he's got epilepsy'. Not 'he may have'".

Donna's extract clearly illustrates that the clinical uncertainty inherent in the diagnosis of epilepsy was frustrating and stressful for her. What likely compounded her frustration was that her son had originally been misdiagnosed twice, so her search for answers at this stage felt even more pressing. Indeed, diagnoses are often sought and valued because they provide an explanatory framework (Jutel, 2009, 2011; Jutel and Nettleton, 2011). Additionally, Donna's quote highlights the argument that not receiving a diagnosis can be distressing (Dumit, 2006; Nettleton, 2006; Jutel, 2009, 2011). However, here parents experienced the distress rather than the person with the condition.

Further complicating the process of receiving the diagnosis was the nature of the condition. Seizures are intermittent and people are often unconscious during their seizures; as a result, if they are not witnessed by another person it can be hard to determine what is wrong with someone based purely on their post-ictal phase (the period following a seizure). This is likely to be a problem for the diagnosis of adult as well as childhood epilepsy. However, the fact that this condition had developed during childhood did add to the diagnostic uncertainty. For one family this became more apparent as the child got older. Chelsea, Robert and Marie's daughter, had started having seizures when she was around four years old; she was medicated and became seizure free and was then weaned off her medication at the age of seven. However, after being discharged from the hospital her

seizures started again. Below Robert is describing the difference between the two periods of seizure occurrence.

Well, this is the difference, when it first happened she [Chelsea] was four, five years old so she couldn't articulate what was going on. She couldn't explain what was happening. So you could just see the outside.

Chelsea's parents speculated that they had not noticed her seizures until they had become more pronounced because she had not been able to describe her seizures when they first occurred. Supporting this contention, when Chelsea started having seizures again she said that her arm kept going numb; when Marie and Robert reviewed videos they had taken of Chelsea when she was four years old they could see that she would use her left arm to pick up and move her right arm and thought this was probably because her arm had been going numb but she had not been able to tell them. This example shows that the occurrence of the condition during childhood meant that symptoms were sometimes harder for parents to interpret and for consultants to diagnose because younger children either did not have the vocabulary to describe their seizures, or possibly did not think these sensations were unusual.

For some parents the diagnosis of epilepsy was a shock. However, similarly to arguments made previously regarding adults' experiences of diagnosis (Lillrank, 2003; Jutel, 2009, 2011; Jutel and Nettleton, 2011), for other parents it was a relief to finally have a label for their child's condition and to know that they would then be treated. Parents who fell into the latter category were often those who had gone through long periods of uncertainty waiting for a formal diagnosis. Critically, however parents felt about their child's diagnosis they tended to see this as an end point to some of their uncertainty – they could now label the child's seizures as a symptom of epilepsy, and often as a particular type of seizure.

However, diagnosis did not end all uncertainties experienced by parents. Indeed, diagnosis often created new uncertainties. For instance,

many parents then felt uncertain regarding the cause of their child's condition. Only four of the 24 children in the study had a form of epilepsy where an underlying cause for their seizures had been found. However, of these four children, parents in only two families knew why their child had developed brain abnormalities. Similarly, Scambler (1983) found causal uncertainty to be prevalent among his sample of adults with epilepsy. Unfortunately, parents reported that often consultants could not answer their questions relating to causal uncertainty, illustrating that clinical uncertainty can prolong parents' uncertainty when answers are not available. Furthermore, in much the same way that diagnosis created new uncertainties related to the cause of the condition, it also created new day-to-day uncertainties, which will be the focus of the following section.

4.3 Day-to-Day Uncertainty

The day-to-day uncertainties that families were living with are the focus of this section. To begin, three types of symptomatic uncertainty are discussed – firstly, similarly to experiences of symptomatic uncertainty among those with chronic pain (Honkasalo, 2008), colitis (Kelly, 1992) and Parkinson's disease (Pinder, 1988), uncertainty regarding the timing of the child's symptoms will be outlined; secondly, uncertainty associated with the severity of symptoms is the focus; and thirdly, uncertainty relating to whether the child had had a seizure will be explored. Finally, the 'cycle of uncertainty' will be discussed, which appears to relate specifically to childhood epilepsy; parents talked about how they were unsure about which changes in their child could be attributed to the child's age and which were a result of seizures, medications or the condition more generally.

4.3.1 Symptomatic Uncertainties

Regardless of whether children's symptoms were well controlled or if they were still regularly having seizures, families lived with the ongoing uncertainty related to the timing of the child's next seizure. Indeed, nine of

the 10 children said they were unsure about when they were going to have seizures. In fact, Isaac (9) was the only child who had a few seconds warning that he was about to have a seizure and described feeling his seizures beginning when his eye and face felt 'ticklish'.

Because the children could not specify when their seizures would occur, or had very little warning, it is not surprising that this was a whole family experience and that parents and siblings also spoke about this type of uncertainty. For instance, Catherine explained:

They [seizures] happen all through the day and to a greater or lesser extent just depending on, I don't know. I don't know what. You can't predict epilepsy, can you? That's the hardest part about it.

Catherine's uncertainty regarding the timing of her daughter Molly's seizures is clearly illustrated in this extract; she begins to talk about what causes fluctuations in the frequency of Molly's seizures but realises that she has no way of explaining this. Moreover, the majority of parents in this study agreed with Catherine that the unpredictability of the condition was a particularly hard aspect to deal with. The prevalence of discussions relating to this type of uncertainty is probably why it is the main type of uncertainty mentioned in previous studies on people with epilepsy (Schneider and Conrad, 1983; Scambler, 1989; Iphofen, 1990; Weinbren and Gill, 1998; Reis, 2001; Jacoby, 2002; Admi and Shaham, 2007).

It was not just children like Molly, who had seizures every day, whose symptoms were seen as unpredictable. For instance, parents of children who were currently seizure free could not be sure how long seizure control would last. For example, Heather commented 'it's just that not knowing. We're not going to know whether it could come in two months or six months. We'll have to wait and see'. Therefore, although every child's epilepsy and seizures differed from one another, all were seen by parents to be inherently unpredictable. Furthermore, although some of the children had triggers for their seizures, they could still experience spontaneous

seizures. Consequently, the same uncertainty relating to the timing of seizures still existed. However, not having any identifiable triggers seemed to compound this uncertainty for some parents as it resulted in feelings of helplessness; as Nicola said, there was ‘nothing’ parents could do to ‘stop what could happen’.

Siblings also spoke about not knowing when their brother or sister’s seizures would occur. For instance, when Zoe (16) was asked about the frequency of her sister’s seizures, she replied:

It’s every other night, I think. It used to be literally every night, maybe once or twice or sometimes more. But I think, I don’t know really, it’s just, sometimes it’s funny, like she [Rosie] won’t have one for like three or four days and then she has two one night. Yeah, it’s all over the place really.

Zoe began her response by trying to answer the question by specifying a pattern to her sister’s seizures, but her uncertainty regarding the timing of seizures becomes more apparent and she ends by saying ‘it’s all over the place really’. As can be seen from the above discussion, uncertainty relating to the timing of seizures seemed to be a whole family experience.

Beyond the uncertainty associated with when seizures were going to occur, parents were also unsure about how severe the child’s next seizure would be. Those that were longer were often deemed to be more severe by parents because children’s breathing becomes shallower when they are having a seizure and *status epilepticus* (prolonged seizure activity) can result in brain damage or death. When speaking about this type of uncertainty, Steve commented ‘the next one could be another great big one’. Related to uncertainty about the severity of seizures, parents could not be sure how long the child’s post-ictal phase (period following a seizure) would last. For instance, Catherine explained:

Sometimes it’s [post-ictal phase] only five minutes, sometimes it’s an hour, depending on how bad that particular one [seizure] was. So it’s very different. Every day is a different thing.

As Catherine described, longer seizures tend to be followed by a longer post-ictal phase. Therefore, because parents could not be certain about the severity of their child's next seizure, they could also not be sure how long their child's post-ictal phase would last. Many children slept when in a post-ictal state, which meant planning activities could be hard because daily life could not immediately continue when a child's seizure had ended. Indeed, as Catherine commented, every day was different in many families.

Family members were not only unsure about when the child's next seizure would occur and how severe it would be; the third type of symptomatic uncertainty that many children and parents experienced was that they were sometimes unsure about whether they/their child had had a seizure. It was mentioned above that many of the children did not know when their seizures were going to occur; similarly, eight of the 10 children were, at times, not sure whether they had had a seizure. When Lydia (12) was asked if she knew when she had had an absence she replied 'I sort of do', illustrating her uncertainty.

Lydia went on to explain how she could sometimes tell she had had a seizure; she said 'it's either at school when I realise I've missed something or I just suddenly come back and it's just like 'ooh''. Although Lydia had learnt to interpret her disorientated feeling following an absence as an indication that she had probably had a seizure, not all children did this. It seemed that that younger children found making this link the hardest, possibly because they had had the least time to become familiar with their symptoms or because, according to parents, younger children had the least understanding of their condition. For example, Samantha explained that her son, Harry (8), would sometimes continue walking whilst having a seizure and that when he regained consciousness he would:

Say things like 'somebody tried to steal me'. He tries to rationalise it in his head and he'll go 'somebody tried to steal me' or 'that lady's got the same coat on as you'. And he's trying to rationalise why he's sort of lost some bearings of what's going on.

Consequently, the uncertainty for children like Harry was not always whether they had had a seizure, but what had happened more generally.

Children's uncertainty about whether they had had seizures resulted in parents often feeling uncertain as well; if parents suspected their child had had a seizure the child was not always able to give them a definitive answer. For instance, the following interaction occurred between Nicola and Steve.

Nicola: He [Zak] thinks he had one [a seizure] on Friday at school, doesn't he? He thinks he had a seizure at school.

Steve: No, well, he thinks [he did]. I'm pretty sure he did.

Steve says he is 'pretty sure', but not that he is certain. However, in the same way that Lydia described how she had learnt to recognise her seizures, parents also found ways to determine whether their child had had a seizure – this will be discussed further in the section on reducing uncertainty.

Related to uncertainty about whether children had experienced seizures was parents' uncertainty regarding what was associated with the condition. This particular type of uncertainty is referred to here as the 'cycle of uncertainty', and is discussed in the following subsection.

4.3.2 The Cycle of Uncertainty

Twenty of the 23 children's symptoms had changed over time; those who experienced multiple types of seizures had often started with one type and others had developed later on. For instance, Donna explained that her son, Noah, had originally experienced absences, but later developed tonic clonic seizures and more recently had started jerking movements, which were becoming more 'noticeable'. Even parents whose children had not developed new types of seizures often found that the way in which seizures presented themselves had changed. For example, when Steve was speaking about reading back through the seizure diary he and his wife kept, he said:

The earlier ones you can read and understand that it's a simple, you know, he [Zak] just stops and stares and starts looking up to the left; whereas now they're [seizures] doing so many different things.

Consequently, children's epilepsy was not seen to be stable and these changing symptoms contributed to parents being on, what will be termed here, a 'cycle of uncertainty'. This cycle of uncertainty appeared to be related specifically to childhood epilepsy because neither the condition nor childhood were deemed to be stable. Each time the child presented a new behaviour parents began on the cycle – firstly, parents tried to determine if the behaviour was normal for the child's age or whether it was related to the condition; secondly, if they thought it did relate to the child's epilepsy, they wanted to know specifically how to define it. Often the only definitive end to this cycle was for the behaviour to be diagnosed by a consultant as a side effect of treatment, a result of the condition or as a certain type of seizure.

The first stage of this cycle of uncertainty was illustrated by many parents who spoke about currently being uncertain about whether some of their child's behaviour was normal for their age or related to the condition or its treatment. Sarah gave one example of this when she was discussing her son's performance at school.

So honestly, I don't know whether it's him [Chris], whether it's a side effect of the epilepsy or what, but definitely his [attainment] levels were lower at the beginning of the year, kind of got them back up again and they've gone back down again. And I'm unsure as to why.

This extract shows that the first stage on the cycle of uncertainty was very similar to the uncertainty parents had initially described when they were talking about the onset of the child's condition. However, rather than trying to determine purely whether a behaviour was a cause for medical concern, here parents, like Sarah, were unsure about whether what they had noticed was linked in some way to the child's existing diagnosis. Consequently, the child's diagnosis of epilepsy and their ongoing treatment for the condition

complicated parents' explanatory tools. In the past, childhood had been their main frame of reference, but now epilepsy was another alternative.

During Steve and Nicola's interview they questioned whether their son's behaviour was linked to his medication, they suggested that his 'stropy' moods could be a sign that a seizure was imminent and they also commented that they had not had a teenager before so they were not sure what was 'normal' for his age. This deliberation suggests that they were also experiencing this first stage on the cycle of uncertainty. Additionally, Steve suggested that this was a problem that 'someone needs to come up with an answer for'. It seems that, again, much like parents' initial uncertainties regarding what children's seizures were, parents were relying on medical professionals to answer their questions as a way of ending their uncertainty. This reliance on the medical profession illustrates that having the ability to provide a diagnosis gives medical professionals authority (Jutel, 2009, 2011; Jutel and Nettleton, 2011).

The second stage on the cycle of uncertainty was reached when parents decided for themselves that their child's behaviour was a result of their condition without confirmation from medical professionals; this did not mean, however, that their uncertainty was entirely resolved. For instance, Samantha explained that she carried a small diary with her where she would note anything 'unusual' that happened to her son. Below, she is describing one regular occurrence that she was monitoring.

Quite often he'll [Harry] just come really pale and he'll say 'I don't feel good. I feel sick'. And then he'll say 'I feel odd. I feel really odd'. And then after about 10 minutes or half an hour, and he has a lie down on the sofa, he's fine and back to being hyperactive and playing or whatever. So I don't know whether they're auras or that's a type of partial [focal] seizure. And again, when you talk to the doctors they don't really say anything. They just go 'OK' and write it down. And that's it.

This extract shows that Samantha had tried to explain these occurrences by drawing on her son's original diagnosis. Furthermore, she had researched

different types of seizures, which supports those who have argued that individuals are more informed than in the past (Conrad and Stults, 2010; Jutel, 2011), primarily because medical information is now 'e-scaped' (Nettleton, 2004). However, Samantha was still uncertain as to what type of seizure this might be. Consequently, as Jutel (2011) has argued, despite the lay public being better informed, the medical profession still maintains its authority as the process of diagnosis gives medical professionals the 'last word'. Samantha ends by stating that the consultants she has spoken to have not been able to answer her questions. Indeed, parents felt that, by themselves, they could only come close to the end of the cycle – they could never be completely certain. For instance, Samantha also commented:

I don't know ... sometimes we put things down to epilepsy that perhaps aren't. And sometimes we don't put things down to it that perhaps are. But nobody's got any definitive answers at all. That's the most frustrating part really.

Consequently, despite parents' suspicions the only definitive end to this cycle of uncertainty was for the behaviour to be diagnosed by a consultant as a side effect of treatment, a result of the condition or a certain type of seizure.

However, this is not to say that parents uncritically accepted medical professionals' opinions. There were many instances when parents described how they had raised concerns with their child's consultant and been told that there was no link to the condition, but parents were not always convinced. However, they could still not be entirely certain without having their suspicions, albeit strong suspicions, confirmed by a medical professional. For instance, Heather said she was not sure whether her son's medication was resulting in side effects or if his behaviour was related to his age. She explained that she had raised this concern with an epilepsy nurse, who had asked the consultant and she was told:

Through the epilepsy nurse, she came back to me and said 'oh, she [the consultant] says it's nothing to do with the medication because he's [Ross] been stable for a while'. That's something I

don't agree with. I think it can affect him off and on. As I said, if there's anything else going on it could trigger something. Or maybe if he has a cold and on the medication that might make it worse. I don't think you can say categorically 'that medication has nothing to do with him'.

This extract illustrates that, as Jutel (2011) and Jutel and Nettleton (2011) have argued, lay people are now in a position to contest diagnoses or the opinion of medical professionals. However, it seems that Heather's cycle of uncertainty could only have come to a close if her son's consultant had agreed with her explanation that Ross' medication was contributing to his behaviour. Without this confirmation, although convinced her son's behaviour was linked to the condition, Heather could not be completely certain regarding the way in which it was associated. Consequently, parents often became stuck at various points on this cycle of uncertainty because without a medical professional answering their questions in a way they were satisfied with, they could not feel fully informed about their child's condition. Furthermore, this cycle of uncertainty would potentially begin again in relation to a new symptom or behaviour at some point in the future.

In this subsection it has been illustrated that because neither childhood nor epilepsy were seen to be stable, parents often become stuck in a cycle of uncertainty where they could not be sure which of their child's behaviours were related to the condition. Additionally, it was medical professionals who could bring this cycle to a close (albeit sometimes only by agreeing with parents' suspicions). However, it was not only the present, but also the future that was seen to be uncertain. The focus of the next section is family members' discussions of uncertain futures.

4.4 Uncertain Futures

Although most people feel the future is somewhat uncertain, parents and children with epilepsy talked about how they felt the condition contributed to the future feeling even more uncertain. For the majority of the children this related to whether they would have the condition for the rest of their

lives. Parents spoke about this type of uncertainty as well, but they also talked more frequently about the impact of the condition on the child's future and the possibility of a limited future.

Eleven of the 23 families had been told that their child would not, or was unlikely to, grow out of the condition. However, the other 12 families could not be sure whether epilepsy would feature in the child's future. For example, Marie said:

We can't control it, we can't change it. We don't know how long it's going to last for. We don't know whether she'll [Chelsea] ever grow out of it or whether she'll have it for the rest of her life.

For Marie, and other parents in a similar position, the future was uncertain because they could not predict how long their child's condition would last. As Carol said, 'maybe it will stop as quick as it started'.

Six of the 10 children also spoke about not knowing whether they would grow out of the condition. For example, Rosie (9) talked about questioning her consultant on this topic and how uncertain she felt about the future of her seizures.

Rosie: I don't know if I'll have it [epilepsy] forever. I'm worried if like I have it forever or something like that. You never know really. I just don't want it getting worse, that's the point.

Rosie's extract illustrates another uncertainty about the future. Not only did family members not know how long the condition would last, they also did not know how it would change over time. All parents talked about this uncertainty as well. For example, Anita explained that the type of epilepsy her daughter, Lydia, had had changed since she was diagnosed. She also said 'I'm very conscious that now it's changed to generalised epilepsy, you know, it might change, she might develop a different type of epilepsy'. Therefore, even when parents could be sure that epilepsy would feature in their child's future, they could not be sure what form this would take.

An additional uncertainty relating to childhood epilepsy was what would happen when the child reached puberty. Puberty and teenage years featured in many parents' discussion and always seemed to be perceived as a problematic time during a person's life, which, for their children, would be complicated further by epilepsy. For instance, Marie noted:

From what I've read, puberty and the hormones and everything like that can cause havoc ... It can make them [seizures] more frequent or it can make them a bit more unexpected.

Consequently, parents were often nervous about their children reaching puberty because they could not be sure how this phase in their child's life would be effected by epilepsy.

Not only did parents consider how the condition might develop, they also considered what this meant for their child's future. For instance, Steve wondered how his son would manage if he chose to go to university and live away from home. Three parents also questioned what impact the condition would have on their child's future job prospects, and four talked about how their child may not ever be able to drive.

All of the extracts above relate to family members considering a future and the extent to which epilepsy would feature in that future. However, parents in 13 of the 23 families also questioned how much of a future would exist, and whether that imagined future might be cut short. For instance, parents spoke about the fact that epilepsy could, in some instances, lead to death, as can be seen in Kelly's extract below.

You constantly worry about him [Ryan]. Especially with this syndrome because you know that any seizure could be, you know, could either cause irreparable brain damage or he could have a seizure that kills him, or he could suffer from SUDEP [Sudden Unexpected Death in Epilepsy] ... They're all worries.

Although some parents did talk about the possibility of their child's future being cut short, they still imagined long-term futures for their children also.

Some parents chose to keep information about the possibility of death from the children and their siblings. However, one child who had talked about this possibility with his parents was Zak (13); he said 'if the worst came to the worst then it could be my last day' and 'sometimes I think, you know 'I could die from it''. However, Zak seemed to be the only child who had pondered this topic.

The above extracts have shown that parents and children with epilepsy were left feeling uncertain about how the condition may develop over time and what implications this may have for the future. The ways in which family members responded to the multiple types of uncertainty described above will be the focus of the next section.

4.5 Responding to Uncertainty

Analysis revealed four primary ways in which family members responded to uncertainty. Zinn (2008) argues that responses to uncertainty fall on a continuum of rationality. However, here it was found that, rather than being rational or non-rational, responses to uncertainty were best understood in relation to the type of uncertainty that was experienced. Firstly, it will be shown that family members, particularly parents, attempted to reduce uncertainty. Secondly, it will be illustrated that when individuals felt the future was too uncertain they responded by shortening their time horizons and living in the present. Next, the focus is on hope and how uncertainties sometimes meant there was the possibility of a positive outcome, as has been found previously (Brown and de Graaf, 2013; Brown *et al.*, 2014; Chen *et al.*, 2015). Finally, when parents knew their uncertainty would one day be resolved or when they had no other choice, they talked about 'waiting'.

4.5.1 Reducing Uncertainty

All parents tried to reduce symptomatic uncertainty relating to the timing of seizures by looking for patterns in their child's seizures. As was mentioned in some of the previous extracts, the majority of parents kept a diary of their child's seizures and what they had done in the lead up to seizures. Parents kept these diaries in an attempt to uncover patterns in the child's symptoms and felt that if they could find what was triggering their child's seizures the condition would be less unpredictable. This is similar to Schneider and Conrad's (1983) argument that adults with epilepsy created certainty by developing theories as to why a seizure had occurred. However, none of the parents felt certain regarding the timing of their child's seizures, and they did not seem to think that they would ever be able to predict the timing of *all* seizures. For example, Steve said 'we've tried to find a pattern in it', but continued to explain that, like many parents, this had not been possible. However, parents continued to look for patterns in an attempt to reduce their uncertainty relating to the timing of seizures.

Another way parents tried to reduce the uncertainty related to the timing of seizures was to look for changes in their child that may indicate a seizure was likely to happen soon. For example, when asked if she or Molly had an indication that a tonic clonic seizure was going to occur, Catherine replied:

I can tell. I mean the last time she [Molly] had one, because they're always in the morning, she was screaming. And I just thought 'OK, I think there's one coming'.

Although Catherine felt she was able to predict that Molly was going to have a tonic clonic seizure, she still could not say exactly when it was going to happen; but this knowledge did help to reduce her uncertainty to an extent. However, other parents had not been able to identify any 'signs'.

In much the same way, parents also looked for signs that their child had had a seizure in order to reduce symptomatic uncertainty relating to whether a seizure had occurred. They did this by becoming familiar with their child's post-ictal state. For instance, Nicola explained:

That's how we've spotted something once before. He [Zak] wasn't sure about whether he'd had one [a seizure] at school before or not, but came home and literally slept for an hour.

The child sleeping was the most common sign that parents spoke about, but Nicola and Steve said another sign they had noticed was that Zak said he would hear sounds differently, Catherine said Molly was sometimes sick and Carol talked about Rosie having 'lines' under her eyes if she had had a seizure during the night. These parents could not be completely sure about whether their child had had a seizure, but these signs did help to reduce their uncertainty.

It was shown above that Lydia had learnt to recognise her absences due to her confusion when she regained consciousness. It seemed that two of the other children had also become familiar with missing parts of their day because of absences. Emma explained that she thought her son, Tom, had learnt to manage this by constantly asking what time it was, as can be seen in the extract below.

Emma: He [Tom] prompts himself a lot by time, he's pretty obsessed by time. Because I do think he misses such huge chunks of the day, if he knows what time it is, he knows where generally he should be up to. So he always asks the time.

Similarly to Tom, Sarah said since starting to have absences her son, Chris, was always checking the time. Sarah believed this was because he was trying to determine whether time had passed without him realising and, by inference, whether he had had an absence. Therefore, this indicates that, although they did not talk about it themselves, some of the children had found ways to determine whether they had had a seizure and how to orientate themselves.

Beyond asking consultants for their opinion, the only way parents tried to reduce their uncertainty regarding what was related to the condition was to do their own research on the Internet and through charity leaflets. As can be seen in some of the extracts above, parents had looked up different types of seizures and side effects of medications to try to help them determine what was related to the condition. This is largely unsurprising as it has already been argued that individuals are now better informed than in the past (Jutel, 2011), primarily because medical information is now widely available on the Internet (Nettleton, 2004; Conrad and Stults, 2010). Nevertheless, as was explained above, parents were often stuck in a cycle of uncertainty despite trying to reduce their uncertainty.

Another response to uncertainty, but this time related to uncertainties about the future, was to try to live in the present. This is discussed in the following subsection.

4.5.2 Living in the Present

One participant who stood out as someone who talked about living in the present was Zak (13). During the group interview when talking through his plan of anything he did on a typical weekday he said:

I put like 'live everyday like it's your last' because even, I wouldn't be taking tablets or doing stuff if it was my last day. If I knew it was my last day I wouldn't be taking tablets, but I guess I've got to do that because if the worst came to the worst then it could be my last day.

As was shown earlier, Zak made a number of references to the possibility that a seizure could end his life. In this extract, he describes how he felt a response to this type of uncertain future was to 'live everyday like it's your last'. This comment indicates that Zak's focus was on the present because he did not know when he would have another seizure, how severe it would be and, consequently, he felt even his short-term future was too uncertain. This is in line with the findings of Brown and de Graaf (2013) and Chen *et al.*

(2015) who studied people with advanced-stage cancer. Therefore, living in the present may be common among those who see the short-term future as uncertain.

However, as was mentioned in the section on uncertain futures, those who spoke about the possibility of a shortened lifespan as a result of epilepsy also talked about a more long-term future when the child, or they themselves, would be an adult. Consequently, this response to uncertainty was not constant, but seemed to fluctuate depending on the extent to which the possibility of death was at the forefront of the person's mind.

Parents in five of the 23 families commented that the unpredictability regarding the timing of seizures meant that it was difficult for them to plan days out or activities. For instance, Emma explained:

If I plan something, it's sort of a running joke in our house, if I plan something one of them [the children] will be ill, but it will generally be Tom. I just hate planning anything because it will, it will happen.

A child having a seizure, or spate of seizures, sometimes meant family activities had to be cancelled or cut short. Consequently, some parents said they chose not to plan activities because there was no way of knowing if the child would be well enough. Alternatively, parents would sometimes only plan things at the last minute. As a result, these families seemed to live in the present even if they did imagine a future. Similarly, Honkasalo (2008), who focused on those with chronic back pain or heart disease, found that people would take one day at a time. Here the focus has been families' responses to uncertainties regarding the not too distant future. A further response to uncertain futures was hope, which is discussed below.

4.5.3 Hope

When the future was uncertain there was always a possibility that there could be a positive outcome, and this is what some family members focused

on. Hope was spoken about specifically but other phrases such as ‘touch wood’ and ‘fingers crossed’ also denoted feelings of hope. Similarly, adults living with advanced-stage cancer have previously been found to respond to uncertainty with hope (Brown and de Graaf, 2013; Brown *et al.*, 2014; Chen *et al.*, 2015). However, hope was not just used by the person with the condition, parents also talked about being hopeful about the future.

Many parents that had not been told whether their child would have epilepsy for life talked about hoping that they would grow out of the condition. Others said they hoped the child’s seizures would be controlled through treatment, or that current levels of control would be maintained. For instance, when speaking about how often her son had different types of seizures, Donna said ‘obviously the big ones now he [Noah] don’t [have them] because his epilim [medication] hopefully, touch wood, sorts that’. Similarly, Rosie (9) commented ‘if I do have it forever, well, [I’ll] just take more, just have more medicine and hopefully it goes’. As this reveals, children hoped for similar outcomes to their parents.

Parents in particular also talked about hope that there would be developments in understanding. For instance, Naomi said ‘it may well change as she [Maisie] gets older and hopefully we’ll get more understanding and things’. There was hope that parents would develop a better understanding of the condition, but also that scientific understanding would improve, which could answer their questions and/or result in new treatment options.

Hope was also one response parents talked about in relation to their uncertainties regarding the combination of epilepsy and their child becoming a teenager, as can be seen in Anita’s extract below.

As long as she’s [Lydia’s] sensible and carries on taking her medication as she gets older, which I hope she will. I mean I know lots of children who are diabetic get to teenage years and rebel a bit. So hopefully she’ll carry on taking it.

There was a sense in parents' discussions, similarly to Anita, that teenagers were not always 'sensible' or logical, but they could still hope their child would not behave in this way in the future. The final way in which family members responded to uncertain futures was by waiting, which is considered in the following subsection.

4.5.4 Waiting

Waiting commonly featured in parents' discussions of the history of the child's condition, specifically when they were speaking about times when they felt particularly uncertain. For instance, almost every parent talked about waiting for test results and appointments, sitting in waiting rooms and being on waiting lists. Consequently, waiting is something that may potentially feature in many people's stories about uncertainty related to illness. However, some parents also spoke about waiting as a response to uncertainty and they tended to do so either when they knew that one day their question would be answered or when there was nothing they could do presently to answer that question.

Parents were not always sure how their child's condition would progress and whether their seizures would ever be controlled. When talking in the group interview about whether her son's medication would be effective, Nicola said:

So it's just a case of waiting to see. And because he [Zak] hasn't been on any other type of drug before I suppose there is a chance that we could swap to a totally different drug altogether. But we've just got to wait and see ... So it's a bit of a waiting game at the moment, isn't it Zak?

Nicola could not answer this question herself but knew that if different doses and forms of medication (e.g. slow release) had been exhausted without effect that this question would be answered. Therefore, all this family could do was wait.

It was also not possible for parents to know how long a seizure would last. Those who had not been prescribed emergency medications to relieve seizures and whose children's seizures lasted more than a few seconds talked about waiting for seizures to end. Similarly, they said they would 'wait' for the post-ictal phase to pass because they did not know how long it would last.

The fact that these were children who had epilepsy contributed to parents suggesting that waiting was an option. It was shown above that a number of parents felt uncertain about what would happen when their child reached puberty. Parents had no way of answering this question other than waiting until that time came and drawing a conclusion then. For instance, Zara said 'we are kind of waiting that when he [Isaac] puts on weight, and also when he hits puberty, you know, we don't know what's going to happen then'. Therefore, it was not only puberty, but also the fact that children were growing that parents felt uncertain about. In response to these uncertainties all parents could do was wait. It seemed that parents felt that adulthood was a more stable time and, therefore, that these uncertainties related to growth and ageing would be resolved once children reached this stage in the life course. Furthermore, some parents seemed to think that age was associated with competency or better understanding. For example, Heather noted:

Some people can feel their seizures coming on sometimes, they get some warning themselves. Maybe if it is going to happen he [Ross] would somehow get a bit more warning now he's older and understands that that's what's happening. But we'll just have to wait and see.

Here Heather speculates that with age her son may know when his seizures were going to occur, therefore reducing the uncertainty relating to the timing of seizures. However, as she cannot currently answer this question, she finishes by saying she will 'have to wait and see'.

However, parents did not always feel that waiting was a viable option, as can be seen in Sarah's extract below.

I have to admit I went slightly mad and I was standing in the children's A&E department crying my eyes out and telling him [the consultant] 'he doesn't understand. I couldn't wait that long'.

Sarah was describing her response when she was trying to get an appointment to get her son diagnosed. Therefore, it seems that waiting was only seen to be reasonable when there was no way parents could currently get an answer and when the wait was acceptable in relation to the uncertainty experienced.

4.6 Conclusion

This chapter has answered the research question that asked how children and their family members experience living with childhood epilepsy. It has been argued that uncertainty was a significant aspect of family members' epilepsy experiences. In accordance with Adamson (1997) it has been shown that it is helpful to break the concept of uncertainty down to reveal a deeper understanding of people's experiences of uncertainty. However, here experiential uncertainty has been broken down further to reveal the multitude of uncertainties experienced by children with epilepsy and their family members. As has been noted in previous studies on epilepsy, one of the most common forms of uncertainty associated with the condition related to the timing of seizures (Schneider and Conrad, 1983; Scambler, 1989; Iphofen, 1990; Weinbren and Gill, 1998; Reis, 2001; Jacoby, 2002; Admi and Shaham, 2007). However, additional types of uncertainty that were prevalent here related to the onset of the condition and having to initially interpret symptoms, diagnostic uncertainty (previously mentioned by Schneider and Conrad, 1983) and causal uncertainty (previously mentioned by Scambler, 1983). Furthermore, two additional types of symptomatic uncertainty (relating to the severity of the next seizure and whether a seizure had occurred) were frequently experienced. Additionally, a cycle of

uncertainty regarding what was related to the condition and uncertainty about what would happen in the future were also found to be commonplace.

Parents described two types of uncertainty that had featured in the past. Firstly, many parents explained that they had initially felt uncertain about whether the child's seizures were normal childhood behaviours or a cause for medical concern. It has been argued that Bury and Holme's (1991) concept of the 'social clock' could be utilised and extended to explain this experience; it can be seen that the child's stage in the life course was taken into consideration when interpreting their behaviour. Furthermore, from parents' discussions it appeared that medical professionals also drew on their social clock to diagnose the child's symptoms. Secondly, parents described diagnostic uncertainty and, in accordance with others (Dumit, 2006; Nettleton, 2006; Jutel, 2009, 2011), it was found that this type of uncertainty could be distressing. However, here it seemed that it was parents who found a lack of diagnosis particularly troubling. Indeed, misdiagnosis and prolonged diagnostic uncertainty often resulted in parents losing faith in medical professionals.

Related to these two initial forms of uncertainty, it has been suggested that parents often faced a cycle of uncertainty, which seemed to be related specifically to childhood epilepsy. As neither the condition nor childhood were seen as stable, parents could not be sure which changes in their child were associated with the condition and which were normal for their age, mirroring the uncertainty experienced around onset. If parents did believe the child's behaviour was related to the condition they could not define specifically what type of seizure this might be without receiving a diagnosis from a medical professional, highlighting Jutel (2009, 2011) and Jutel and Nettleton's (2011) argument that diagnosis significantly contributes to medical authority. As a result, parents often became stuck on this cycle of uncertainty. Furthermore, it seemed that this process would start again every time the child presented a new behaviour or symptom.

Additionally, four responses to uncertainty were evident in parents and children's remarks – reducing uncertainty, living in the present, hope and waiting. Although Zinn (2008) talked about hope as a potential response to uncertainty, he categorised responses to uncertainty on a continuum of rationality. However, here it has been shown that responses to uncertainty are context specific and, as a result, hope reflects a situated rationality. Consequently, based on the discussions presented above it is argued that rationality was not an appropriate means of categorising responses to uncertainty, rather it appeared that these responses were primarily related to the type of uncertainty that was experienced.

For instance, reducing uncertainty principally related to uncertainties regarding the timing of seizures and whether a seizure had occurred. Schneider and Conrad (1983) described how people with epilepsy created certainty by developing theories as to why a seizure had occurred. However, here, rather than creating certainty parents attempted to reduce uncertainty by looking for triggers, signs their child may have a seizure, or signs that they had had a seizure. Similarly, some of the children had learnt to recognise signs that they had had a seizure.

As has been found previously, uncertainties relating to the future could be responded to by living in the present (Honkasalo, 2008; Brown and de Graaf, 2013; Chen *et al.*, 2015) and/or by hoping for a positive future (Brown and de Graaf, 2013; Brown *et al.*, 2014; Chen *et al.*, 2015). When the future was seen as too uncertain or there was uncertainty relating to how much of a future may exist, parents and one child talked about living in the present. However, living in the present was not a consistent response as all of those who talked about this response also spoke about an imagined future. In relation to imagined futures, if there was uncertainty about what may happen in the future there was a possibility that the future would be positive, and this is what parents and children hoped for.

Furthermore, an additional response to uncertain futures, that has not been discussed in the literature previously, is waiting. Parents talked about waiting when they knew their questions would eventually be answered and when there was no other way to find an answer to their question presently. This response may be related to uncertain conditions in childhood more generally as parents talked about waiting for the child to age to see what would happen in the future.

This chapter has shown that children and parents talked about living with uncertainty as a result of the condition and the ways in which they responded to different uncertainties. These feelings of uncertainty also led to perceptions of risk, which are discussed in the following chapter, as well as how the condition was managed socially.

Chapter Five: Perceiving and Managing Risk

5.1 Introduction

One aim for this chapter is to answer the following research question: How do families manage childhood epilepsy? A dominant theme arising from the participants' use of language when discussing managing the condition was risk; therefore, the findings presented in this chapter focus on how family members' perceived and managed risk. The existing sociological literature on epilepsy indicates that concealment is the most common management strategy used by both adults with epilepsy (Scambler and Hopkins, 1986, 1988; Scambler, 1989, 2011; Iphofen, 1990) and parents of children with epilepsy (Schneider and Conrad, 1980, 1983; Scambler and Hopkins, 1986; West, 1990). Therefore, a second aim for this chapter is to address the research question: To what extent is concealment used as a management strategy for childhood epilepsy in contemporary society? Answering this question will give an indication of whether the ways in which families manage the condition has changed over time. If there has been a change, it may be possible to explain why this has happened.

Sociological theory suggests that we are living in a 'risk society' (Beck, 1992) where individuals use the notion of risk to organise their social worlds (Giddens, 1991). However, it is important to note that the term 'risk' has been conceptualised in a number of different ways (Lupton, 1991; Denney, 2005). The approach that informs the discussion of risk presented within this chapter is that of a 'weak constructivist' perspective (Lupton, 1991, 1999). It has been argued that in a risk society uncertainty is viewed with anxiety and, consequently, uncertain outcomes are seen as risky (Lee *et al.*, 2014). As a result, the idea of risk consciousness – a way of looking at the world where hazards are thought about in terms of risk (Giddens, 1991) – will be drawn upon. Given the high level of uncertainty experienced by family members, described in Chapter Four, it is not surprising that risk consciousness was evident in participants' discussions.

Furthermore, it is argued that social actors have become increasingly 'individualised' (Beck, 1992; Beck and Beck-Gernsheim, 2002). Beck argues that in the past individuals were restricted by social structures and customs, whereas they are now more reflexive, have greater freedom over the choices they can make and, consequently, biographies are 'self-produced' to a greater extent (1992: 135). However, it is argued that individualisation is a double-edged sword, as people are now deemed to be responsible for the choices they make (Beck and Beck-Gernsheim, 2002).

In a risk society children are seen to be a particularly vulnerable group and are, consequently, often categorised as 'at risk' (Jackson and Scott, 1999; Lupton, 1999; Firkins and Candlin, 2006; Meyer, 2007; Lee *et al.*, 2010). Moreover, individualisation has resulted in parents being seen as responsible for protecting their children from risks (Jackson and Scott, 1999; Geinger *et al.*, 2013; Lee *et al.*, 2014). However, Lee *et al.* (2014) draw attention to the 'double bind of parenting culture', where conflicting expert advice means all parenting techniques are viewed as potentially risky and, therefore, parents are perpetually trying to juggle competing risks.

Indeed, it has been found that parents draw on two dominant parenting rhetorics and two different notions of childhood in their discussions on risk. One parenting discourse prioritises protecting children (Jackson and Scott, 1999; Jenkins, 2006; Gabb, 2008; Hoffman, 2010; Gómez Espino, 2013), and the other centres on encouraging children to develop into competent adults by avoiding overprotection (Jackson and Scott, 1999; Backett-Milburn and Harden, 2004; Jenkins, 2006; Gómez Espino, 2013). In relation to notions of childhood, it has been noted that children are seen as 'beings' and 'becomings' (Hockey and James, 1993; Christensen, 1998; Uprichard, 2008); this means that children occupy a dual temporal location, as they can simultaneously be viewed as both 'people now' and 'people for the future' (Mayall, 1998: 275). It is intended that this chapter will add to the parenting literature by exploring how discourses on childhood and parenting interacted with constructions of risk, and how such interactions

impacted on the way in which childhood epilepsy was managed within the family.

Additionally, there is only a small amount of sociological literature exploring children's experiences of epilepsy (Weinbren and Gill, 1998; Admi and Shaham, 2007) and many studies that have commented on children's experiences of the condition are based on information gleaned from adults' memories of their childhoods (Schneider and Conrad, 1983; Scambler and Hopkins, 1986, 1988; Scambler, 1989). Furthermore, there has been very little focus on how children manage other chronic conditions (for exceptions see Atkin and Ahmad, 2002; Gabe *et al.*, 2002; Alderson *et al.*, 2006). Given that it has been argued that it is important to access children's views from children themselves (Hockey and James, 1993; James, 1993; Mayall, 1998), it is intended that this analysis will contribute to the literature on the management of chronic conditions by children by providing an insight into how perceptions of risk (both children's and parents') influence children's experiences of living with epilepsy.

Within this chapter it will be demonstrated that parents responded to physical risks by: informing others and manipulating place, activities and/or space. Additionally, the three main responses to risks arising from perceptions of stigma and difference that were used by the children and their parents are illustrated – concealment, selective disclosure and altering ideas of 'normal'. However, in order to address how families managed risk, first, family members' perceptions of risk are outlined.

5.2 Perceptions of Risk

The majority of parents perceived that their child was exposed to physical risks resulting from their epilepsy; however, the children and their siblings spoke less on this topic. Some of the perceived physical risks were new to these families when the child developed the condition; others were pre-existing risks that were reconceptualised and came to be seen as more risky

when viewed through an ‘epilepsy lens’. Family members also spoke about the risk of being socially excluded as a result of the stigma that they perceived to be attached to the condition, but it was the children with epilepsy who appeared to feel this risk was most significant.

5.2.1 New Physical Risks

Parents’ perceptions of new physical risks directly resulting from the child’s condition primarily related to three causes of physical harm. Firstly, all parents thought that seizure occurrence was in and of itself risky. For instance, when speaking about her son waking up early in the morning Kelly used the term ‘risk’ in relation to the possibility of her son having a seizure; she said ‘he [Ryan] will kind of lie down and sometimes doze off back to sleep but then you always run the risk of him having a seizure’. Kelly explained that particular stages of her son’s sleep cycle were triggers for his seizures and that, due to the ‘risk’ of seizures, it was important that she tried to ensure he did not fall back to sleep after he had woken up.

In addition to the perceived risk of seizures, parents in 12 of the 23 families worried about the possibility of SUDEP. For example, Ruth commented ‘because of the risk of SUDEP she’s [Alice’s] monitored 24 hours a day’. Here Ruth again uses the term ‘risk’ to denote both the uncertainty inherent in perceptions of risk and the negative consequences of SUDEP.

Furthermore, parents in 16 families were concerned about the child going into *status epilepticus* (prolonged seizure activity), which could result in brain damage or death. For instance, when speaking about her daughter, Catherine said:

She’s [Molly’s] had quite a few [seizures], one major, really bad, very scary one, which was the last time we called an ambulance because it went on for 25 minutes ... I’m sure you know, the longer they go on the more dangerous they are. That was awful.

As 'danger' is synonymous with 'risk' in contemporary society (Lupton, 1991; Fox, 1999), Catherine's repetitive use of phrases such as 'really bad', 'scary' and 'dangerous' in the extract above clearly demonstrate the risk she associated with *status epilepticus*, which was also echoed by other parents.

Although parents perceived children to be exposed to a number of physical risks directly resulting from their epilepsy, the children spoke little on this subject. Indeed, the only child to discuss any of these risks was Zak (13). For instance, as was noted in Chapter Four, he commented 'if the worst came to the worst then it could be my last day', indicating he felt epilepsy could end his life.

Beyond the risks that were exclusively associated with the child's condition, many parents and children felt there was a risk of incurring injuries during seizures; consequently, pre-existing risks were often reconceptualised and seen to be more risky for the child with epilepsy when viewed through an 'epilepsy lens', compared to the level of risk the same activities or environments posed to children without epilepsy. These reconceptualised risks are discussed in the following subsection.

5.2.2 Reconceptualising Physical Risks When Viewed Through an 'Epilepsy Lens'

It has previously been argued that parents and children conceptualise risk through their own 'biographical lens' (Backett-Milburn and Harden, 2004). In a similar way, risk in these families was often (re)conceptualised using an 'epilepsy lens'. By this it is meant that family members reconceptualised the risks posed by the child's everyday surroundings and activities in light of the potential consequences were the child to have a seizure. Indeed, a number of activities and environments, when considered in conjunction with the child's condition, were perceived to be more risky for the child with epilepsy than other children more generally.

One hazard that was highlighted by a number of parents was the child's exposure to water. For instance, Donna explained her family's routine when they go swimming:

We always make sure when we go swimming there's one-on-one ... instead of me being for Layla [sibling] and Noah, Keith [Step-Dad] will go and stay with Noah alone while I kind of stay with Layla and Amy [step-sibling]. So it's always one-on-one.

Donna clearly felt her son needed closer supervision than his sisters as a result of his epilepsy and the possibility that he could have a seizure in the water. Similarly, heights, roads and night time were other risks that were reconceptualised in many families following the child's diagnosis.

Half of the 10 children also reconceptualised risks in light of their condition and talked about some of the same risks as their parents. For instance, Lydia (12) spoke about the risk of her having a seizure near a road, and Ross (10) commented:

I have to be extra careful that I don't do stupid stuff, like go abseiling, swimming in high water and a rip tide. That's not good, because if I got caught in a rip tide and had a seizure I'd be screwed.

Here Ross talks about being 'extra careful' to guard against risk and the fact that certain environments would be more dangerous if he were to have a seizure. Overall, it appeared that older children were more likely to discuss reconceptualised physical risks, which potentially indicates that children only begin to perceive forms of physical risk as they age. Alternative forms of risk that many of the children, and some of the parents, felt epilepsy presented were a result of their perceptions of stigma and difference, which are described below.

5.2.3 Risks Resulting From Stigma and Difference

There were mixed opinions among family members regarding whether or not epilepsy was stigmatised in wider society. Drawing on Scambler and Hopkins' (1986, 1988) distinction between 'enacted' and 'felt' stigma, where enacted stigma refers to actual instances of discrimination and felt stigma is based on a sense of shame and the fear of being discriminated against, it seemed that the children with epilepsy had the highest levels of felt stigma and siblings were least likely to describe this type of stigma. Furthermore, it was the children with epilepsy and their parents who most commonly described instances of enacted stigma.

Three of the 10 children with epilepsy described instances of enacted stigma. For instance, Rosie (9) said 'this boy said to me 'I hope you die of it'', and in the extract below Harry (8) is talking about other children in his class at school and explaining why he feels stigmatised as a result of his epilepsy.

Harry: They say 'it's because you've got epilepsy you're an idiot' sometimes.

I: So do you not like talking about it sometimes?

Harry: No.

I: Why do you not like talking about it?

Harry: Because I know people are going to make fun out of me like the boys at school do.

This finding contrasts with previous research, where it was argued stigma was learnt within the family (Schneider and Conrad, 1980, 1983; Scambler and Hopkins, 1988), and suggests that children are now more likely to feel epilepsy is stigmatised as a result of their interactions with peers outside the home. This is likely to be because the parents and siblings in these families did not feel epilepsy was something to be ashamed of.

Three additional children, similarly to Harry above, did not like talking about their epilepsy and often responded to questions about the condition with one-word answers or said 'don't know'. The family members of these children also explained that the child would not talk about their

condition to anyone. For instance, Harry's mum, Samantha, said that if she tried to talk to him about his seizures 'then it's straight lockdown'. Similarly, Natasha (11) explained that her brother, Tom, did not like people realising he had had a seizure: 'if we sort of like try and say his name [when he's having a seizure] and sort of get him back into focus he gets annoyed because he doesn't want people to realise'. The children's reluctance to talk about their condition suggests that they felt stigmatised by the condition and, consequently, felt at risk of experiencing instances of enacted stigma. Based on the children's comments above, it seems that the most likely explanation for this felt stigma was instances of enacted stigma by peers.

The siblings were the group who were least likely to discuss felt stigma or the risk of enacted stigma. When asked if they felt others treated their brother or sister differently, five of the 10 siblings said 'no'. The other five siblings explained that their brother or sister received more attention than themselves and they were well cared for, which was predominantly not seen to be negative treatment; although, Natalie (14) did note that well-meaning actions may not always have positive effects:

I think the school does [treat Lydia differently] because they put her in like, she got kept behind because of it, because we didn't know what it was. So she like lost loads of like learning and stuff. But because it's like classed as some sort of disability or whatever she got put in like the complete bottom sets. So like more for confidence but she doesn't really need it. She felt left out all the time because of it.

Although Natalie explained why she thought her sister had been treated this way at school, she felt it resulted in her feeling 'left out'.

In contrast to the other nine siblings, Nathan (11) felt his brother was at risk of being treated negatively if others were aware of his condition, as can be seen in the extract below.

I: Do your friends at school know [Isaac has epilepsy]?

Nathan: Yeah. Because Isaac had a seizure when he was doing a play so everyone saw. And all of the teachers had to just go and pull him out of it.

I: Oh OK. So that's how your friends knew?

Nathan: That's how most people know, yeah.

I: OK. So did anyone say anything to you about it afterwards?

Nathan: They did. I just pretended I didn't really know what happened. It's the easiest thing.

I: Oh OK. So did you not want to talk about it?

Nathan: Yeah, not really.

I: Is there a reason you didn't want to talk about it?

Nathan: Not really. Because I know Isaac probably wouldn't want loads of people to know. Because then he probably would be treated differently.

It was clear from talking to Nathan that he felt if others knew about his brother's epilepsy then the different treatment Isaac might receive would only be negative, which is why he chose not to explain Isaac's seizure to his peers. However, only a small minority of siblings felt their brother or sister was at risk as a result of others' responses to their condition, either because of intentional or unintentional exclusion.

Similarly to the siblings, there were mixed opinions among the parents regarding whether they thought the condition was stigmatised. Parents in eight of the 23 families felt their child was at risk of being socially excluded. Those who felt their child was at risk all described instances of enacted stigma; for example four parents said they thought their child had not been invited to other children's birthday parties because of their epilepsy. Therefore, similarly to the children, among the parents who participated in the study, felt stigma appeared to be closely linked to enacted stigma. This is in contradiction to previous research, which found that levels of felt stigma were far higher than levels of enacted stigma (Scambler and Hopkins, 1986, 1988). It may be that in an individualised society where difference is more readily accepted parents do not expect a medical condition to be viewed negatively by others, and it is only when enacted stigma is experienced that felt stigma develops.

An additional risk that only parents talked about was the risk that children may grow up to have an 'unhealthy relationship' with their condition. Parents in six of the 23 families thought people with epilepsy often resent the condition during adulthood and felt their child was at risk of feeling this way in the future. For example, Robert said:

If it is something that she's [Chelsea's] going to have for the rest of her life then there's nothing she can do to stop that from being there. And if it's a negative thing then it will be a cross to bear. And it's not healthy for somebody to live like that.

Robert therefore felt that there was a potential psychological risk to his daughter if she perceived the condition negatively.

Although there was widespread concern among parents regarding the risks their children were exposed to, they tended to respond in different ways. The ways in which families tried to minimise physical risks are discussed below.

5.3 Managing Physical Risks

Parents had differing opinions on how to, and whether to, minimise the physical risks the child faced as a result of their epilepsy and seizure occurrence. These differences of opinion primarily resulted from the extent to which parents felt the child was at risk. Despite these differences, in accordance with Beck's (1992) concept of individualisation, parents did feel personally responsible for protecting their children; throughout the interviews parents commented that they felt protecting the child from risk was their responsibility as a parent. Furthermore, even when the child was being cared for by another adult, parents often spoke about how they had put measures in place to ensure risk to the child would be managed during that period. The primary ways in which parents tried to minimise or eradicate physical risks was through: manipulation of place and/or activities; manipulation of space; and by informing others about the child's condition, all of which are described below.

5.3.1 Manipulation of Place and Activities

Whether trying to minimise the risk posed by new physical risks or reconceptualised pre-existing risks, parents in 14 families manipulated place and/or activities. Here, 'place' is used to refer to the child's physical environment and surroundings (Backett-Milburn and Harden, 2004) and the term 'manipulation' means that parents controlled and altered the child's access to places and/or activities that they deemed to be risky. Both place and activities are discussed together because they were often interlinked; indeed, certain activities were restricted purely because of the place in which they occurred.

Where possible, parents attempted to reduce the risk of seizures by identifying and avoiding the child's triggers, which were often place specific. For example, Emma commented 'we don't let him [Tom] dive or anything because holding his breath brings them on'. Additionally, Emma said the family avoided noisy or busy places because they could also induce her son's seizures. Other restrictions placed on children in different families in an attempt to avoid triggers were: limiting time spent outside when it was particularly windy or hot, avoiding flashing lights, minimising time spent playing computer games and making sure children were in bed by a certain time if tiredness could bring about their seizures. This supports previous research, which found that one common management strategy used by people with epilepsy was avoiding triggers (Shostak *et al.*, 2011).

However, not all children had triggers for their seizures and those who did would also experience spontaneous seizures; consequently, some parents tried to limit the extent to which children were exposed to the most 'risky' reconceptualised risks. Therefore, many parents limited children's access to certain places, particularly those involving spending the night away from home, water, heights or roads. For example, Sarah said:

There's a little Tesco [supermarket] down there. We used to let him [Chris] go down there for us if we needed milk or whatever.

He'd trot off all proud of himself and he'd go off down there. But once the epilepsy started obviously we had to stop that. So the independence that he had had and he had started to build up was effectively snatched away from him, with good reason when you look at the road.

This extract illustrates the risk Sarah felt the nearby road presented to her son were he to have a seizure, and the impact this had on the places she felt comfortable allowing him to go alone. Similarly to Sarah's statement above, parents in 17 of the 23 families noted that they had altered their child's independence or activity participation as a result of the onset of the child's epilepsy.

Some alterations and restrictions on activity participation affected not only the child with epilepsy but the whole family. For example, in order to avoid children becoming over tired families often left events early or cut days out short, which meant parents and siblings also had their activities adjusted. Some families also avoided particular holiday destinations either because of the length of journey or the risk that the child would have a seizure abroad and not be able to receive the necessary medical care. Furthermore, Hannah, Jack's mum, felt her family was unable to go to many places as a family, as she describes below.

We can't get into the car without having to do a risk assessment about where we're going ... We've been out twice in the last two years, I think, as a family ... We do things separately or without Jack.

Again, Hannah frames these restrictions as resulting directly from her perceptions of risk. Similar adjustments to family members' activity participation have been found in relation to families that had a member with asthma, colitis, cystic fibrosis or a disability (Nocon and Booth, 1990; Kelly, 1992; Bluebond-Langer, 1999; Prout *et al.*, 1999; Stalker and Connors, 2004; Barlow and Ellard, 2006).

Parents felt that the restrictions placed on children's activity participation tended to, or would, become more apparent as children got older. This is likely to be because it is expected that children will become more independent as they age (Jackson and Scott, 1999; Backett-Milburn and Harden, 2004). Similarly to some of the extracts above, five parents commented that children were at an age where they would have been gaining more independence and freedom but this had been limited because of their epilepsy. For example, Nicola said 'if he [Zak] was now getting to the stage where actually he wanted to branch out and try new things, there could be a restriction on that'. Similarly, Anita commented that the restrictions on her daughter, aged 12, were not expected for a child her age.

Anita: She [Lydia] doesn't have the freedom her sister had at this age because she'd walk into the road if she was having them [seizures] ... The fact she doesn't have the freedom that she probably should have at that age, that's quite a big thing. Yeah, that's quite a big thing really.

These extracts show that parents felt a tension between two parenting discourses – one emphasising the importance of children developing into independent adults (Jackson and Scott, 1999; Backett-Milburn and Harden, 2004; Jenkins, 2006; Gómez Espino, 2013), and the other constructing parents as responsible for protecting children (Jackson and Scott, 1999; Jenkins, 2006; Gabb, 2008; Hoffman, 2010; Gómez Espino, 2013). Indeed, these extracts clearly illustrate the 'double bind' of parenting culture described by Lee *et al.* (2014). In these instances the latter discourse centred on protecting children from risks was given priority when deciding how to manage the child's condition.

Despite the widespread manipulation of place and activities, these restrictions were not necessarily thought to be permanent. Many parents hoped for a time in the future when restrictions on activities and access to particular places could be lifted. These decisions regarding restrictions were often associated with parents' perceptions of seizure control. This

fluid nature of risk perception was evident in some families where parents felt the child's seizures were now controlled. For instance, Heather said:

He [Ross] doesn't really not get to do anything because we do let him go swimming and go on his bike and stuff. And I'd quite happily let him climb trees and things.

However, she also noted that:

When he first had them [seizures] it was very much, he was only 7 but he would have had a bit more freedom. Like we were just across from the shop, there wasn't a road to cross or anything, I would have sent him over to the shop to get himself something. We didn't do anything like that. We didn't go swimming for quite a while ... And the bike riding was off for a bit. He didn't have baths for a long time, it was just a shower and sort of trained him not to lock the bathroom door.

These extracts suggest that parents' perceptions of risk were not necessarily fixed. Instead, based on parents' statements, perceptions of risk appeared to change over time depending on their views of the child's seizure control. This finding, therefore, supports existing arguments regarding the contingent nature of perceptions of risk (Lupton, 1999; Backett-Milburn and Scott, 2004).

Furthermore, although parents frequently manipulated place and/or activities, a number of parents did not respond to all physical risks in this way. Eight parents spoke specifically about how they had chosen not to restrict their child's activity participation. The primary reason for this choice was because parents normalised the physical risks to the child. For example, Carol spoke about her daughter's injuries as a result of her seizures as a normal aspect of childhood when she said 'she's [Rosie's] hit her arms and she's got bruises on her legs, but most children have, haven't they?' Similarly, although Marie did not see SUDEP as normal, she did feel that childhood accidents were normal occurrences. Below she is explaining her reaction to being informed about SUDEP by her daughter's consultant:

It's one of those things we just ignored. Because what ifs. What if, she [Chelsea] could have walked, fallen down the stairs and broken her neck. She could, you know, well, the amount of things that go horribly wrong from one minute to the next with kids is just unbelievable.

Marie took a fatalistic view towards the possibility of SUDEP and normalised the risk by explaining that she felt it was no different to any other physical risk present during childhood.

When parents spoke about their choice not to impose restrictions on the child's activities they often talked about 'not wrapping children up in cotton wool'. For example, Marie said:

We let her [Chelsea] go on climbing frames and we let her continue to do everything she did before. And it was kind of like 'we'll deal with it. If she gets hurt, we'll deal with the consequences afterwards'. Because, you know, she's 5 and you can't wrap them up in cotton wool. That's how they learn to survive. And if she has it for the rest of her life, she has to learn to live with it.

Marie not only felt this was important for children generally, she also strongly bound this idea to her role as a parent. For instance, she said:

It's our job to make sure that when she [Chelsea] grows up she knows how to deal with it and how to cope with it, without it having an adverse effect on her life.

Therefore, some parents justified their decision not to manipulate the child's access to certain places and activities, which potentially exposed them to physical risks, by drawing on the parenting discourse associated with raising children to be competent adults (Jackson and Scott, 1999; Backett-Milburn and Harden, 2004; Jenkins, 2006; Gómez Espino, 2013).

Similarly to Marie's statement above, many parents were aware they were not always going to be able to manage the risks presented to their child and felt it was important that children learnt to manage risk for themselves. This is illustrated by Donna's comment below.

Whether he [Noah] has epilepsy or not, he has to be a little boy. He has to develop and self manage. If he's going to climb, he's going to fall ... He's got to look at risk and harm and balance for himself and work it out.

This extract demonstrates that Donna did perceive there to be physical risks to her son, but also that she felt he needed to learn to manage these himself. In these instances parents were not only prioritising parenting discourses that relate to encouraging children to grow into independent adults (Jackson and Scott, 1999; Backett-Milburn and Harden, 2004; Jenkins, 2006; Gómez Espino, 2013), they were also placing emphasis on the future adult. This contrasts with the previous extracts where parents focused on the current child. Therefore, it can be seen that these two parenting discourses are inherently linked to the dual temporal location within which children are located in Western societies (Mayall, 1998).

Although these two parenting discourses appear to contradict one another as one is based on protecting children from risks and the other condones exposing children to some risks so they learn to manage risks themselves, these two discourses existed alongside one another in a number of parents' interviews. For example, Kate said:

If we go to Nan's or something and it's in, again, a closed in garden or something, there's nothing that he [Max] could hurt himself on especially more than anyone's garden. You know, if you fall down on concrete it's going to hurt. But that would be the same whether he had epilepsy or not and you can't wrap them up in cotton wool.

Here Kate is drawing on the latter discourse. However, she also noted during her interview that she limited the amount of time her son spent playing computer games because she felt they induced his seizures and he had a strict bed time of 7.30pm because tiredness was another of his triggers. Furthermore, Kate commented:

He's only recently learnt to ride his bike without stabilisers but I wouldn't be OK with him riding it along the street next to a road

because if he were to veer off or something then, it's just not worth the risk.

Although Kate believed Max was exposed to risk in both extracts, she responded to these differently depending of the level of risk she felt her son was exposed to as a result of his surroundings. Therefore, in line with previous research, these two parenting discourses existed simultaneously (Jenkins, 2006). Which discourse parents drew on depended on their perceptions of risk and whether they felt alterations to place and/or activities would lower these risks presently or in the long term. Where current risks were perceived to be high, alterations to the child's activity participation were often made; however, when current risks were perceived to be low many parents prioritised the future adult and deemed it acceptable to expose children to such risks.

Despite the widespread use of manipulation of place and activities by parents, none of the children said they felt their lives were particularly limited as a result of their condition. Six of the 10 children in the present study felt that epilepsy did not limit their daily activities, and the four who did saw the limitations to be minor. For instance, when Zak (13) was asked if there was anything he was not allowed to do because of his epilepsy, he replied 'well, they [doctors] said the only job you can't do is join the army, which is quite good actually'. Interestingly the only restriction Zak felt epilepsy had on his life was on his future employment prospects. However, Zak's parents, Nicola and Steve, described a number of restrictions on their son's activities (including not being able to use public transport to get to and from school and not allowing him to go on school trips abroad or day trips with his friends). Therefore, Zak may have either been unaware of these restrictions, did not associate them with his epilepsy, or, possibly, was not bothered by them. The finding that children did not think epilepsy limited their lives is in contrast to previous research conducted by Weinbren and Gill (1998), with six children aged 8-12 years in the UK, where it was found that:

One of the most striking aspects of the children's stories is their perception of the continuous ordeal of having epilepsy. They are constantly aware of its effect on their school life, holidays, friends, and family. (Weinbren and Gill, 1998: 59-60)

A potential reason the findings of this study are different to the research quoted above is because many of the children interviewed here were unaware of the extent to which their parents manipulated their access to certain places and/or activities.

Although the manipulation of place and activities was common it was not the only way in which parents responded to physical risks. A further means of reducing the physical risks children were exposed to was through the manipulation of space, which is discussed below.

5.3.2 Manipulation of Space – Supervision and Increasing Proximity

All parents felt they were able to reduce the risk presented by the child's epilepsy by manipulating space. 'Space' is defined here as the physical distance or perceived proximity between the child with epilepsy and a person caring for them (Backett-Milburn and Harden, 2004). Consequently, parents often manipulated space by supervising children, thereby increasing their proximity to the child. This is, therefore, another reason some parents did not limit their child's activity participation, or only placed restrictions on children being alone in certain places, as they felt risk could be managed by manipulating space rather than place. Although 'space' is discussed as distinct from 'place', it is acknowledged that supervising the child meant the child's physical environment had been altered due to the presence of another individual; however, supervision is nevertheless considered to be a manipulation of space as it was through increasing their proximity to the child that parents felt that risks had been managed.

Parents used supervision in response to the same reconceptualised risks that they also managed by manipulating place. For example, many

parents supervised their children around water, as the following extract illustrates.

Emma: He [Tom] goes swimming with school and he has someone in the pool with him, purely because he can go literally like that. It's so quick.

Swimming was one of the most common activities that parents viewed as risky and they either supervised children or ensured another adult who was aware of the child's condition did to minimise the risk of injury or drowning if the child was to have a seizure. This finding supports previous research on parenting, where it has been found that parents often use supervision to reduce the level of risk posed to their child (Firkins and Candlin, 2006; Jenkins, 2006; Gómez Espino, 2013). Furthermore, Reis (2001) also found that parents used supervision in an attempt to minimise risk in her research involving parents of children with epilepsy in Holland.

In the sociological literature on parenting, it appears that in addition to 'where' questions, 'when' questions are often considered by parents when they are deciding if a child should be supervised (Jackson and Scott, 1999; Sarre, 2010). For example, many parents viewed a child being outdoors alone at night as more risky than the same scenario during the day (Jackson and Scott, 1999). However, the parents in this study discussed when supervision was necessary less regularly because many felt the risk epilepsy presented was constant due to the unpredictable nature of the condition. Consequently, these parents chose to ensure the child was supervised, either by a family member or another adult, all the time. For example, Samantha said 'He's [Harry] with an adult 24/7. Whatever the adult is, school, whatever, he's always with an adult 24/7'.

Moreover, some parents perceived night time or times when the child was asleep to be particularly risky. Consequently, parents in eight of the 23 households altered family members' sleeping arrangements so that the child could be monitored during the night. Two parents had purchased

double beds for the child's bedroom so they could sleep in the same room and bed as the child. Similarly, three parents, particularly single parents, moved the child into their bed. The other three set up additional beds in either the child's or their own bedroom so that they could sleep in the same room. For some these were permanent alterations to their sleeping arrangements, and for others they were temporary and fluctuated between the child sleeping in their own bedroom alone or with siblings to sleeping with a parent. Williams *et al.* (2000) found that parents were more likely to make alterations to sleeping arrangements when their child was diagnosed with epilepsy in comparison to diabetes, which the authors defined as an equally risky condition. The present research suggests that a reason for this difference could be parents' perceptions of the level of risk presented by the conditions.

Even when parents were not directly supervising their child they still felt that increasing their proximity to the child could reduce risk. For instance, when discussing an upcoming school trip Steve and Nicola said:

Nicola: But that's a big move. And actually we're going to have a little sneaky support network in place that we're not going to tell anyone about, which is that Steve is literally going to follow the coach up to London by car, lurk in London for a few hours and follow the coach back without the school knowing.

Steve: And him knowing.

Nicola: And most importantly without Zak knowing.

Therefore, parents felt their proximity to the child could reduce the physical risks associated with epilepsy. This finding could be because parents did not fully trust others caring for their child to respond to their symptoms appropriately. However, Nicola commented 'we have no doubt at all that in the care of school [he will be looked after]'. Therefore, parents may not have felt comfortable deferring responsibility to others, as they believed themselves to be individually responsible for their child's safety. In some cases this meant the child could feel they had some freedom and independence and parents could still feel they were close by. Increasing

proximity was, therefore, one way in which parents could balance the tension between protecting children and allowing them to participate in age appropriate activities 'unsupervised'.

Alternatively, some parents manipulated space by creating 'virtual proximity' (Bauman, 2003) through the use of technology, such as mobile phones. In doing so they were able to feel the distance between themselves and their children had been reduced. Three parents felt they could allow children some independence as long as they carried a mobile phone with them. This was illustrated by Heather who said 'we got him [Ross] his mobile phone so he could pop over to his friend's house as long as he had his phone'. Parents saw this as a way of being close or in contact with children should they have a seizure and regain consciousness. In the same vein, parents ensured others with the child also had a mobile phone, again so they could be contacted. This finding supports Jenkins (2006) who found that parents commonly use mobile phones to increase proximity to their children. This is likely to be because, as Lupton argues, the use of digital devices can 'blur spatial boundaries for their users' (2015: 170). Indeed, Bauman notes that 'proximity no longer requires physical closeness; but physical closeness no longer determines proximity' (2003: 62).

Similarly, parents in nine of the 23 families used technological devices to reduce the feeling of distance between themselves and their children during the night. Two families used bed alarms that would wake the parent if the child had a seizure, and seven used baby monitors so they could monitor the child over night without having to be physically in the room with them. Therefore, parents were again using technologies to create virtual proximity between themselves and their children.

Rosie (9), however, was not keen on the idea of a baby monitor, as the following extract demonstrates.

I: You know your Mum said last time I was here that she was thinking about getting a baby monitor?

Rosie: Yeah.

I: And you didn't want her to. How come you don't want her to get one?

Rosie: I don't want to be a baby all the time. I don't really want one.

This particular type of monitoring technology, therefore, had infantile connotations that Rosie did not want imposed on her as she got older.

However, none of the children spoke negatively regarding the increased levels of supervision or surveillance that were currently in place. When Noah (5) was asked if there was anything he was not allowed to do because of his epilepsy he replied 'go far', indicating that even the youngest children were aware they were sometimes supervised. Some even saw this positively, as Lydia's (12) comment illustrates:

They look after me more and make sure I'm with someone that's like, if I'm out they make sure I'm with someone I can trust in case I daydream [have a seizure] near a road or something.

Within this subsection it has been shown that parents responded to the physical risks presented by the child's epilepsy by manipulating space, which involved increasing levels of supervision and/or increasing their physical proximity or sense of proximity to the child through the use of technologies. The final way in which parents reduced the level of physical risk to their children was by informing others about the child's condition, which is discussed below.

5.3.3 Informing Others

All the parents that were interviewed also felt that they could reduce physical risks to the child by informing anyone taking responsibility for the child about their epilepsy. For instance, Samantha said 'if he's [Harry's] in someone's care they're definitely told'. Informing others was at the forefront of many parents' minds when releasing their child into someone

else's care. For example, Sarah noted: 'when he [Chris] goes to friends' houses and stuff I always say, the first thing I say is that he has epilepsy'.

Parents felt it was necessary to inform others, such as teachers, those running extra-curricular activities and their children's friends' parents, because they wanted to make sure that anyone caring for the child would recognise their seizures and care for the child appropriately if they were to have a seizure. It is important to note that parents always said disclosing their child's epilepsy was a way of protecting the child, rather than a way preparing others 'for the shock of witnessing a fit' (Weinbren and Gill, 1998: 66). Therefore, here parents' focus was on their child rather than other people.

In instances where parents chose not to inform others about the child's condition this was either because they were present or they did not feel the child was exposed to physical risks as a result of their seizures. Below Kate is talking about occasions when her son has had an absence.

Someone will say something to him [Max] and it's like, because he hasn't heard it, they might as well have not said it. So he goes off completely. As far as they're concerned, completely ignores what they've just said. And I let him. And I think 'well, I can't always be there to rescue him'. He needs to learn that that is what's going to happen. Sometimes that's never going to get fixed. He's going to have broken conversations possibly all his life.

As can be seen in Kate's extract, in instances where the child was not perceived to be at physical risk, information about the child's epilepsy was not always passed on to others. In the previous extracts protecting the child was the dominant discourse; however, in Kate's extract her focus was on the future adult and the need for her son to learn to manage his condition by himself. The fact that parenting discourses and the dual temporal location of the child are interlinked is, therefore, again illustrated.

The different ways in which parents responded to the physical risks they felt their children were exposed to as a result of their condition have been outlined in this section. Now, family members' responses to the risks associated with stigma and difference will be addressed. Furthermore, children's thoughts on their parents informing others about their condition will also be discussed.

5.4 Managing Stigma and Difference

The following subsections detail the three main ways in which children with epilepsy and/or their family members responded to the risks of being stigmatised as a result of their epilepsy or growing up to resent the condition. Some of these responses were primarily adopted by the children with epilepsy, and others were only used by parents and siblings.

5.4.1 Concealment and Selective Disclosure

In line with Goffman's (1963) arguments on managing stigma and previous research on adults with epilepsy (Schneider and Conrad, 1981, 1983; Scambler and Hopkins, 1986, 1988; Scambler, 1989, 2011; Iphofen, 1990), three of the six children who appeared to feel at risk of being stigmatised by the condition often opted to conceal their epilepsy from others. For instance, when Tom was asked if he ever spoke to anyone about his condition he replied 'no'. Tom's mum, Emma, supported him in a separate interview when she said 'Tom won't speak about it'.

In contrast, all parents said they would disclose the child's condition for their safety. However, four did say they had made a conscious decision not to conceal the child's epilepsy. For instance, Donna said 'I mean at first I was a bit like 'do I tell them? Do I not?' And I have told some'. Rather than blanket concealment, therefore, parents who did feel the condition was stigmatised were more likely to opt for selective disclosure. Unlike parents who were completely open about the child's condition, these parents

carefully chose who they would confide in. The decision to tell others about the child's epilepsy was often driven by their perceptions of physical risk, as is illustrated in the following extract.

I: Do you still make people aware?

Emma: Only when I have to.

I: Right, OK.

Emma: Like I say, only when I have to. I wouldn't introduce Tom and say 'he's got epilepsy'. If he was invited round someone's house for tea I would have to say he's got epilepsy. I'd begrudgingly say it, but you have to for Tom's safety.

Therefore, as in the example above, physical risks tended to be prioritised over non-physical risks by parents.

Like Emma, some parents who felt the condition was stigmatised were selective in who to disclose information about the condition to and felt children should be able to do the same (where perceptions of physical risk did not override the child's choice). For example, below is Samantha's response when asked if her son's friends knew he had epilepsy.

I don't know if they do know or not. I've never said to any of his [Harry's] friends. I know some of the parents know because I've told them. But I don't know if any of his friends know. And in my opinion that's his news to tell, not mine.

However, some children did not get this choice and did not appreciate the decision to disclose being made for them, illustrated in Ross' (10) extract below.

I: So do people at school know you've got epilepsy?

Ross: Not at this school, no. But at my old school then yes.

I: How did they know at your old school?

Ross: Because my mum told everyone.

Ross' disapproval of his Mum's actions was clearly articulated through his irritated tone of voice. Similarly, Anita explained that her daughter, Lydia (12), did not like her bringing up the topic of epilepsy with her teachers.

Anita described how she had emailed Lydia's school because she had had a brace fitted during the school holidays and that this had made Lydia nervous of talking in front of others. Anita felt that anxiety was a trigger for her daughter's seizures and wanted to inform the school so they could monitor her seizure activity. However, Anita said 'she [Lydia] found out I'd emailed them and she went mad - 'Why have you emailed them?!' Therefore, parents and children sometimes disagreed over whether or not to speak about the condition to those outside the family. Similarly, it was found that children with thalassaemia major and their parents had conflicting opinions regarding what was in their best interest in relation to managing the condition (Atkin and Ahmad, 2002).

Rather than blanket concealment, the other three children who felt at risk of enacted stigma as a result of the condition opted for selective disclosure, like their parents. These children moved between concealment and talking to others about their condition. For instance, Isaac's brother, Nathan (11), said:

If he's at somebody's house he'll usually either, he can feel it coming on so he'll usually pretend he's going to the toilet and he'll hide behind the sofa or something.

Isaac (9) supported this when he said 'I'd try to get away and then let it [the seizure] happen' when he was speaking about feeling a seizure coming on at school. However, Isaac also said he did talk to some friends about his epilepsy. Below he is explaining that he did not want epilepsy to become a dominant feature of his identity or what he was known for among his wider peer group.

Isaac: I can remember in year 2 I had one [a seizure] during an assembly and I was on stage. Everyone saw me ... And then all day everybody was asking me what happened ... I didn't like it because it was happening all day. I didn't mind just a few people but it's just all day.

Similarly Rosie (9) described talking to her friends about having glue in her hair after she had had an EEG, but said she did not like it when ‘everyone’ kept asking what was in her hair. These examples show that these children were comfortable talking to selected peers about their epilepsy but did not want to be known to others because of the condition. This may be because within the peer group children place emphasis on ‘sameness’ and ‘conformity’ (James, 1993). Schneider and Conrad (1980) too argue that the epilepsy ‘closet’ has a revolving door and people may choose to be ‘in’ or ‘out’ in different situations at one point in time. It, therefore, appears that children with epilepsy use selective disclosure in the same way as the adults in Schneider and Conrad’s (1980) study.

As well as managing risks associated with stigma, parents also managed the risk that the child may grow up to resent their condition. Parents managed this risk by altering their ideas of ‘normal’, which is the focus of the following subsection.

5.4.2 Altered Ideas of ‘Normal’

Parents who perceived feeling different to be a risk because they thought the child would grow up to begrudge their condition tended to respond by altering their ideas of normal to include epilepsy and/or its symptoms. For instance, Robert said:

We want it to just be like Marie said ‘well, you’ve got blonde hair’ or you’ve got whatever. So we made a lot of effort for it to be just perfectly normal. So we didn’t overreact whenever it happened and all that kind of thing. It was all ‘oh yeah. That’s cool. Don’t worry about it’ ... It just became normal. It sounds really strange to say but it became normal ... We made an effort for it to be normal.

Throughout the interview Marie compared epilepsy to a number of different things including: having blonde hair, long nails and wearing glasses. Marie and Robert had actively chosen to expand their ideas of normal to include epilepsy and its symptoms. This is similar to the cognitive element of

Kelleher's (1988) definition of normalisation. In his work on diabetes he described how people normalised their lives, in part, by coming to view their symptoms as normal.

Alternatively, rather than demedicalising the condition and seeing epilepsy as normal, one parent constructed having a medical condition as something that was normal; Carol said: 'she's [Rosie's] got a problem that she has to be medicated for but then there's millions of people who do for all different reasons'. Another family altered their ideas of normal to include the child's symptoms, but not necessarily the condition as a whole. Kate said she did not want to risk her son growing up feeling he had to apologise to others if he had a seizure; she said 'don't apologise, that's how you [Max] are'. Kate, like two other parents, viewed her son's seizures as part of who he was. The difference between Kate's and Marie's comments is that Marie viewed her daughter's seizures as being normal for anyone and normalised the condition more generally, whereas Kate viewed her son's seizures as normal for him, but not necessarily others; in this way seizures were sometimes incorporated into families' perceptions of the child and their identity. However, the extent to which parents normalised the condition and/or the child's symptoms in order to counteract the risk of them feeling different varied depending on the type of seizures the child experienced. Indeed, normalisation was more likely if children had absences or forms of seizures that were less obvious to others. This is likely to be because absences can be subtler compared to other types of seizures and many parents saw them as less risky.

Parents often encouraged other family members to view epilepsy and/or seizures as normal. Children with epilepsy rarely adopted this view, which is likely to be because they had higher levels of felt stigma when compared to other family members. However, siblings were more likely to accept seizures as a normal occurrence. For example, when describing his sister's reaction to his seizures Zak (13) said:

She's [Chloe's (6)] really casual, acts like it's a normal thing really. She just walks over to Mum and Dad, she just goes 'Zak. Fit.' [Laughs]

Although some siblings felt their brother or sister's seizures had become a normal and recurrent feature in their lives, the extent to which this was the case differed depending on previous experiences and the type of seizures the child had; it tended to be that siblings talked about feeling scared or worried if their brother or sister had been hospitalised due to a seizure in the past or if they had tonic clonic seizures.

5.5 Conclusion

The findings in this chapter have answered the research questions relating to how families manage childhood epilepsy and the extent to which family members use concealment as a management strategy in contemporary society. The findings lend support to those theorists that argue that we are living in a risk society where discourses on risk are dominant in daily life (Giddens, 1991; Beck, 1992). Indeed, risk consciousness was high as ideas on risk were regularly articulated and parents perceived their child to be exposed to a number of risks as a result of their epilepsy. Furthermore, the findings are in line with Beck's (1992) and Beck and Beck-Gernsheim's (2002) argument that society is more individualised than in the past and that people now feel individually responsible for the choices they make; parents appeared to feel solely responsible for protecting their children and felt somewhat torn between the various parenting options open to them. When parents were responding to risk they overwhelmingly prioritised physical risks. Parents were found to use three main strategies to minimise the physical risks presented by the condition. Parents manipulated place and/or activities and informed others about the child's condition. They also manipulated space by supervising the child and increasing their proximity to the child; this could be physical proximity or 'virtual proximity' (Bauman, 2003) through the use of technological devices.

Children on the other hand tended to guard against the risk of being stigmatised by their peers. Some children who felt stigmatised by the condition, in line with Goffman's (1963) arguments on managing stigma and previous research on adults with epilepsy (Schneider and Conrad, 1981, 1983; Scambler and Hopkins, 1986, 1988; Scambler, 1989, 2011; Iphofen, 1990), often attempted to conceal the condition from others. The other children who felt at risk were more likely to selectively disclose the condition, similarly to Schneider and Conrad's (1980) concept of the 'revolving door', as a way of avoiding epilepsy becoming an identifier or dominant feature of their identity. It is argued that children who selectively disclosed their condition opted for this as a result of children placing emphasis on 'sameness' and 'conformity' (James, 1993).

Some parents also opted to use selective disclosure if they thought the child might be stigmatised by the condition. Additionally, parents responded to the risk that their child might feel different as a result of their epilepsy by altering their ideas of normal to include the condition and/or its symptoms. This is similar to one element of Kelleher's (1988) definition of normalisation, as he argued that people came to view their symptoms as normal.

Additionally, half the children who did feel stigmatised by the condition spoke about how these feelings developed as a result of their interactions with those outside the family. Therefore, as none of the children spoke about feeling stigmatised as a result of a family members' actions, this contradicts the idea that parents act as stigma coaches (Schneider and Conrad, 1980, 1983) or that stigma is learnt within the family (Scambler and Hopkins, 1988). It could be that the findings of this study differ from previous research because it was only during the 1970's that children started to be constructed as 'at risk' (Lee *et al.*, 2014). As the research cited above was conducted with adults, they would have grown up during an earlier period when parents were possibly more focused on

protecting the family from being stigmatised, rather than protecting the individual 'at risk' child.

The findings also differ from previous research that has indicated people with epilepsy feel stigmatised but experience few instances of enacted stigma (Scambler and Hopkins, 1986, 1988; Jacoby, 1994), as many of the children who felt stigmatised said that instances of enacted stigma from their peer group had led them to feel that way. However, as almost half of the children and the majority of family members did not feel stigmatised by the condition, in line with other empirical evidence, the extent to which epilepsy is stigmatised among the general public may have reduced (Scambler and Hopkins, 1986; Jacoby *et al.*, 2004), which is now being reflected in lower levels of felt stigma.

Furthermore, throughout this chapter it has been shown that parents drew on two parenting discourses – one related to protecting children from risks (Jackson and Scott, 1999; Jenkins, 2006; Gabb, 2008; Hoffman, 2010; Gómez Espino, 2013), and the other emphasising that parents are responsible for encouraging children to grow into competent adults (Jackson and Scott, 1999; Mayall, 2002; Backett-Milburn and Harden, 2004; Jenkins, 2006; Gómez Espino, 2013). It has previously been argued that although these discourses may appear contradictory, they can in fact exist alongside one another (Jenkins, 2006), and this was found to be the case in a number of parents' interviews. Additionally, it has been argued that children in Western societies occupy a dual temporal location – they are seen both as current children and future adults (Mayall, 1998). Within this chapter it has been demonstrated that the parenting discourses discussed are intimately linked to these two different temporal locations of children. It has also been argued that these two cultural phenomena (parenting discourses and perceptions of children) influenced parents' discussions of managing childhood epilepsy; parents prioritised physical risks to the current child and only when risks to the current child were perceived to be minimal would they move their focus onto the future adult.

Overall, it has been shown that family members perceived epilepsy to present physical and non-physical risks to the child. The ways in which these risks were managed within the family have also been outlined. An additional way uncertainty relating to the timing of seizures, and consequently risk, was dealt with was by treating the condition in an attempt to control the child's seizures. The chapter that follows focuses on the meanings that parents and children attached to three household treatments for childhood epilepsy.

Chapter Six: The Meanings of Household Treatments²

6.1 Introduction

This chapter explores the meanings family members attached to three household treatments for childhood epilepsy – antiepileptic drugs (AEDs), emergency medications³ (administered in response to prolonged seizure activity) and the ketogenic diet. By exploring the meanings children and their parents attached to AEDs and emergency medications the following research question is answered: How do family members view medications for childhood epilepsy? Additionally, parents' experiences of using three forms of ketogenic diet – the classical ketogenic diet, the Medium Chain Triglyceride (MCT) diet and the Modified Atkins Diet (MAD) – will also be considered. As the findings presented relate to all three diets, with no major discrepancies between them, for the sake of clarity they are referred to collectively from now on. Consequently, this chapter also addresses the research question: How does implementing the ketogenic diet affect the meanings attached to foods?

There is some literature exploring the meanings adults attach to medications (van der Geest and Whyte, 1989; Britten, 1996, 2008; Whyte *et al.*, 2002; van der Geest, 2010; Chamberlain *et al.*, 2011; Dew *et al.*, 2014, 2015), particularly prescription medications (Helman, 1981; Gabe and Lipshitz-Phillips, 1982, 1984; Conrad, 1985; Shoemaker and Ramalho de Oliveira, 2008; Webster *et al.*, 2009). Prescription medications for chronic conditions can be viewed with ambivalence. For instance, Gabe and Lipshitz-Phillips (1982, 1984) found that women saw benzodiazepines as

² Some of the material presented within this chapter has been accepted for publication in *Sociology of Health and Illness* (Webster and Gabe, 2016). A copy of the paper is included in the appendices (Appendix 26).

³ This discussion of emergency medications is limited to those that are stored within the family domain and administered by family members; intravenous and other emergency treatments administered by medical professionals will not be discussed because the focus of this thesis is on childhood epilepsy within the family, rather than in the clinical setting.

'evil necessities'. Such ambivalence is often linked to the side effects that accompany medication use (Pound *et al.*, 2005; Britten, 2008; Chamberlain *et al.*, 2011) and the perception that pharmaceuticals are not natural (Gabe and Lipshitz-Phillips, 1984; Britten, 1996; Whyte *et al.*, 2002). However, medications can also be viewed positively. For example, Shoemaker and Ramalho de Oliveira (2008) argue that when a medication helps to relieve debilitating symptoms it can be seen as a magic elixir. More generally, medications are valued because they promise a return to health (van der Geest, 2010). Pharmaceuticals can also be viewed positively because they allow treatment to remain personal as drugs can be administered discretely (van der Geest and Whyte, 1989; van der Geest, 2010).

Despite the wealth of knowledge on the meanings adults attach to pharmaceuticals, little has been written regarding children's views on medications. Almarsdóttir and Zimmer (1998) explored factors influencing 7 and 10-year-olds knowledge of medications; however, they focused on children without chronic conditions. Consequently, the meanings children attach to medications used to treat chronic conditions have been largely neglected. It is, therefore, intended that this study will begin to address this gap in the literature by detailing the meanings children with epilepsy attached to their medications and how these compare to the meanings adults ascribe to medications.

This chapter also looks at the experience of using dietary treatment. As was illustrated in Chapter One, there has been an increase in the number of families using the ketogenic diet to treat childhood epilepsy over the past two decades (Wheless, 2008; Lord and Magrath, 2010; Payne *et al.*, 2011). However, this diet is yet to be researched from a sociological perspective. Due to its high fat content, the ketogenic diet contradicts ideas about what is a 'healthy' diet (Lupton and Chapman, 1995; Lupton, 1996, 2005; Counihan, 1999). Furthermore, food has significance for the family as a whole because love and care are displayed through feeding others and sharing food (DeVault, 1991; Lupton, 1996; Warin *et al.*, 2008). Moreover, the cultural

ideal of the 'family meal' is still aspired to in many families, as it is seen as a social event that brings family members together (James *et al.*, 2009; Stapleton and Keenan, 2009). Due to its high fat content and because children on the ketogenic diet are unlikely to be able to share food with their family members, it would be interesting to know how these characteristics of the diet affect the ways in which parents view ketogenic foods.

Research focusing on families' responses to the use of dietary treatment by a family member for other medical reasons indicates that other family members often assimilate dietary changes by adjusting their own food consumption, either for practical reasons or to normalise dietary alterations (Gregory, 2005; Pitchforth *et al.*, 2011). This response has been found in families where one family member had diabetes (Kelleher, 1988; Maclean, 1991), a nut allergy (Pitchforth *et al.*, 2011), coeliac disease or coronary heart disease (Gregory, 2005). An alternative response, found in families where a child had coeliac disease, was to demedicalise the diet by treating food consumption as 'a matter of choice rather than prescription' (Veen *et al.*, 2013: 592). The ketogenic diet differs somewhat from the diets that have previously been studied; due to the restrictions inherent in the diet, and because it should be medically monitored, it is highly unlikely that all family members would be able to take on the same dietary alterations. As a result, there is scope to add to the current literature on the use of dietary treatment within the family by exploring the meanings attached to the ketogenic diet and how implementing it affected family eating practices.

This chapter is split into three main sections. Firstly, the meanings attached only to medications are explored (medication as prevention and medication as an unpleasant necessity). Secondly, the meanings attached to ketogenic foods are discussed (food as medicine, fat as good, food as a symbol of inclusion and food as a symbol of love). Lastly, the meanings attached to both medications and dietary treatment will be outlined (treatment as a symbol of difference and treatment as a saviour).

6.2 Meanings of Medications

When examining the meanings that were applied to the different treatment methods it was evident that two of the meanings were attached specifically to medications. Firstly, medication as prevention is explored. Although this meaning may appear implicit, it seemed that this was not always the case for the children, as some initially believed medicines were cures. Consequently, children seeing their AEDs as a form of prevention sometimes developed over the course of treatment. Secondly, medication as an unpleasant necessity is discussed; it will be illustrated that children and parents drew on different considerations when constructing this meaning.

6.2.1 Medication as Prevention

All parents in this study referred to the obvious reason for their child's medication use – prevention of the child's seizures. For instance, Heather, Ross' mum, said:

He's [Ross] been on it so long and there's enough evidence to say that he won't, probably won't, you know, really good chance that he won't have a seizure when he's on it ... I feel comfortable when he's on the medication that it's not going to, there's the same chance as there is for any other kid that it's going to happen.

This extract illustrates that Heather had faith that her son's medication would prevent his seizures. Although Heather could not say for certain that Ross would not have a seizure when on his medication, she reformulated her response a number of times to make the point that she was 'comfortable' when her son was taking his medication. However, it was not only parents whose children had experienced complete seizure control that viewed daily medication in this way. Parents of children who still had seizures all commented on a reduction in the frequency or length of their child's seizures and, consequently, also saw AEDs as a preventative measure.

Children principally viewed their daily medications as a way of preventing their seizures as well. For example, when asked ‘what would happen if you stopped taking your medicine?’, Ross (10) replied ‘I would have another seizure sometime’. The extract below, from Rosie’s (9) interview, is illustrative of a similar sentiment:

Rosie: The medicine, that’s, I just want it to stop that really.

I: You want to stop the medicine?

Rosie: No.

I: You want it to stop your fits?

Rosie: Stop the fits. I don’t know how really they can do it but they’ve done it really well.

Rosie’s comments indicate that she did not have complete faith in her medication to stop her seizures entirely; however, she did hope that they would and felt that this was a possibility given how effective she thought her AEDs had been thus far.

Although all of the children viewed their daily treatment as an ongoing way to prevent their seizures, there was evidence to suggest that two of the children had initially viewed their treatment as a cure. For example, the extract below is from Ross’ (10) interview when he was asked why he had previously stopped taking his medication.

I: Did you think you were going to have seizures again when you stopped taking it or did you think they’d gone away?

Ross: I hadn’t had one for about a year and a half so I thought ‘OK, that’s close enough’.

Similarly, below Zara is explaining that her son, Isaac, had originally seen his medication as a cure, rather than a preventative measure.

He [Isaac] doesn’t do it now, but only up until very recently he’s had this idea that once he stops having fits and everything’s running smoothly that he doesn’t actually need his medication anymore. And he’s only just started to get the idea that it’s the medication that stops the fitting.

These statements show that the idea of treatment being a preventative measure had to be developed by Ross and Isaac in accordance with the chronic aspect of the condition. It has been noted that medications are often valued because they symbolise the promise of a return to health (Whyte *et al.*, 2002). As can be seen above, these two boys, based on their previous experiences of treatment (antibiotics and pain killers), seemed to believe that medications were indeed cures; consequently, when their symptoms were no longer present they thought they did not need to take their medication. However, it was evident that this interpretation had been adjusted because, when interviewed, these two children both described currently seeing their medications as a form of prevention. From parents' perspectives, it was necessary that children learned to view their medications as a preventative measure because, like the statements above suggest, if they did not view their AEDs in this way they were less likely to continue taking them when their seizures were controlled.

Despite children and their parents seeing AEDs as beneficial because they were helping to control their seizures, medications were rarely viewed in a wholly positive way, as we see below.

6.2.2 Medication as an Unpleasant Necessity

It was found that parents and children, at times, saw medications as what can be most appropriately described as an unpleasant necessity. This meaning encapsulates the view that although medications were not liked or enjoyed, they were deemed to be a necessary feature of daily life. In this sense this meaning is similar to the 'evil necessity' meaning described by Gabe and Lipshitz-Phillips (1982, 1984) in relation to their work on benzodiazepines. However, the unpleasant necessity meaning differs as participants never described medications in such a damning way. Moreover, the way in which some children described their AEDs was more in accordance with the phrase 'unpleasant'.

The chronic nature of the child's treatment had negative implications for the ways in which daily AED treatment was thought about by parents. Indeed, parents in 19 of the 23 families who were asked expressed concerns about the side effects of treatment, and this was particularly troubling for parents because the treatment was ongoing. For instance, Kelly explained:

It's getting that balance between him [Ryan] having a few breakthrough [occasional] seizures but him being the least drugged up that he's been, or increasing the drugs but seeing a decline in his [ability to participate in] day-to-day [activities].

This extract shows that Kelly viewed AED treatment as an unpleasant necessity in that although it was intended to reduce the frequency and severity of her son's seizures, there were also side effects to take into consideration. This supports Chamberlain *et al.*, who note that it is common for medications taken for chronic illnesses to be positioned as 'necessary, but taken with reluctance' (2011: 303).

Similarly, in two of the 11 families where emergency medications had been prescribed, parents also viewed these as an unpleasant necessity, as they had somewhat conflicting feelings about this type of treatment, as can be seen in Catherine's comment below.

I'd never want that [*status epilepticus* – prolonged seizure activity] to happen again because we had to give her [Molly], because she has Buccal [emergency medication]. And I don't like having to give her that because it can slow your breathing down. It's not a nice thing to have to give your daughter when you're, well, you don't want to really. You just want her to come back when she's fitting for that length of time.

Catherine's statement illustrates that she felt she had to administer Molly's emergency medication in order to stop her seizures, but also that she did not actually want to because she was concerned about potential side effects of the drug. Consequently, Catherine saw this type of medication as an unpleasant necessity. An alternative meaning that was more commonly attached to emergency medications is described later on.

As in the instances above, parents' perceptions of, and attitudes towards, their child's medications were influenced by their personal experiences and the perceived changes in their child that they believed to be the result of treatment. However, in line with previous research, parents' views were also influenced by information provided by lay sources (Stevenson *et al.*, 2008; Dew *et al.*, 2014) and what they read on the Internet (Ziebland, 2004; Dew *et al.*, 2014). Indeed, parents in 17 of the 23 families had researched their child's medication online and read about the side effects others had attributed to particular drugs and additional uses for these medications. For instance, Heather commented:

I don't know what effect it is having on him [Ross]. It is for bipolar so the thing is, if it's not stopping his seizure activity and he doesn't need it, what's it doing to his brain? Because it must have some effect if it's able to control adults with symptoms like that.

Here Heather's perception of her son's medication was influenced by the fact that she found out that it was also used to treat mental illness. As a result of her views on this type of illness and its treatment, she was concerned about the impact these drugs may be having on her son. This is in accordance with previous research that has found that the meanings attached to medications can be influenced by perceptions of the conditions they are intended to treat (Whyte *et al.*, 2002; Shoemaker and Ramalho de Oliveira, 2008; Dew *et al.*, 2015). Additionally, people tend to attach negative meanings to drugs if they view them to be too 'strong' or aggressive (van der Geest, 2010). Consequently, Heather's comments, and those presented above, are illustrative of Webster *et al.*'s (2009) assertion that individuals make sense of medications using 'lay pharmacology', which is in part influenced by their own experiences and the experiences of others.

Overall, despite negative perceptions of the child's AEDs, all parents continued treatment as they felt the preventative aspect of continued medication use outweighed the actual or potential negative implications of the drugs. This is consistent with previous research that has found that those taking medications over long periods of time often make trade-offs

between symptom control and side effects (Shoemaker and Ramalho de Oliveira, 2008). However, although all parents were currently in a position where they viewed their child's AEDs as an unpleasant necessity, those in 14 of the 23 families explained that in the past they had requested their child be changed to a different medication when treatment was deemed to be ineffective or when side effects were not seen to be worth the benefits gained. Therefore, although AEDs were generally seen as an unpleasant necessity, in the past, certain AEDs had not been viewed in this way; rather they had been seen as too unpleasant to be necessary, as there were other drug options available.

Although daily medications were viewed as a way of preventing their seizures, some children also currently saw, or had previously seen, AEDs as an unpleasant necessity. Eight of the 10 children commented that they either currently did not like their medication or that they had not liked it in the past. For instance, Rosie (9) said 'I don't really like it. It tastes like, it tastes weird. It doesn't taste nice at all'. The majority of the children who said they did not like taking their medication were referring to liquid medications and commented, similarly to Rosie, that this was because of the taste of the liquid. However, they preferred to take the medication rather than have seizures. For example, Rosie (9) also said 'if I do have it [epilepsy] forever, well, [I'll] just take more, just have more medicine'. Therefore, AEDs in liquid form were seen as an unpleasant necessity by the children as the process of taking these drugs was not viewed as enjoyable, but rather as necessary due to the desired result of controlling their seizures.

Although it was overwhelmingly liquid medications that were viewed as unpleasant by the children, two children also viewed tablets in this way. In the past Lydia (12) had chosen to stop taking her tablets because she had difficulty swallowing them. Thus, like a number of parents, Lydia had also decided that the negative aspects of her treatment outweighed the positives. However, this decision was the result of different considerations to those of the parents (difficulty ingesting medication rather than side effects). In all

instances where children then became able to swallow their tablets, tablets were no longer seen as unpleasant. As a result, these children saw their medication only as a necessity rather than an unpleasant necessity.

This subsection has illustrated that both parents and children, at times, saw household medications for childhood epilepsy as unpleasant necessities. However, this view was more widespread among parents as not all children saw their current medication in this way. Similarly to the way in which some meanings were only attached to medications, others were only associated with ketogenic foods, which are discussed below.

6.3 Meanings Attached to Ketogenic Foods

The focus of this section is the meanings attached to foods consumed by children on the ketogenic diet. It was argued in Chapter Two that the ketogenic diet contradicts a number of cultural food norms. Parents were aware of these contradictions, which at times led them to feel guilty because they felt they were not fulfilling their parental responsibilities. In the interview extract below Alison and Paul are describing their emotional reactions when their son initially started the diet.

Alison: I think at first it was quite, it was the guilt. You know, we're sat here eating a Yorkshire pudding and a roast potato...

Paul: With these big beady eyes looking at you and you're thinking 'I can't cope with this'.

Alison: Yeah. At the beginning we never ate together, did we?

Paul: No, no.

Alison: Because we felt too guilty knowing that he [Connor] couldn't have...

Paul: What we were having.

Alison: Things that he loved. He loves food.

This illustrates the guilt parents felt by denying children foods they desired, which was heightened when parents themselves were eating those exact foods in the presence of the child. However, in order to overcome this

problem, parents sometimes altered the meanings attached to food. The first altered meaning is discussed in the subsection below.

6.3.1 Food As Medicine

Despite the ways in which the ketogenic diet contradicts a number of cultural food norms and the fact that parents' emotions were tied to their child's food consumption, families were able to overcome these contradictions. Firstly, as described by Naomi in the following quotation, parents attached new meanings to the child's food:

I do sometimes think 'oh, I should really give her [Maisie] more variety'. But you kind of have to start thinking of food as medicine. You don't have to have too much emotion attached to it.

DeVault (1991) notes that norms related to feeding others tend to be referred to more directly when people feel that they are unable to follow these norms; a feature which was common in parents' discussions about the diet. Indeed, this is what Naomi is doing here when she acknowledges the importance placed on consuming a varied diet. However, Naomi then describes how she overcame this contradiction – by viewing food as medicine. It is acknowledged that medicines are not always viewed positively (Britten, 2008), as can be seen in parents discussions of AEDs above; however, in this instance, parents used this terminology to express the beneficial impact this treatment was having on their child.

This view of food as medicine is in stark contrast to Veen *et al.*'s (2013) research on families with a child with coeliac disease, where it was found that dietary alterations were demedicalised. Instead, parents in this study drew on the medical model – the dominant approach to illness in Western society that assumes an underlying pathological cause of illness and gives authority, regarding the diagnosis and treatment of illness, to those in the medical profession (Bury, 2013). Drawing on this model enabled parents to view food functionally in the sense that they saw the

entirety of the child's food consumption as a treatment for their condition. Naomi describes how, by viewing food in this way, some of the meanings attached to food became irrelevant. Indeed, when these meanings were stripped away, the child's food could be thought of purely in terms of the benefit this dietary treatment was having: all parents claimed there had been a reduction in their child's seizures, many described other benefits such as increased alertness and some said they had been able to reduce the child's medication as a result of the diet and felt this had resulted in fewer side effects.

When speaking about creating meals, parents tended to talk about the child's food in a scientific or calculated way. They spoke about the child's 'prescription' – the amount of fat, protein and carbohydrate each meal had to contain – again linking to the idea that food is medicine. Below are quotations relating to the three different diets that effectively illustrate the way in which food was thought about. The type of diet being referred to is given in brackets at the end of each statement.

Paul: He's [Connor's] on a 4:1 ratio. (Classical)

Hannah: We've just tweaked the diet again, so at the minute it's 29 fat [points] and we're up to 9 carbs. (MAD)

Kelly: When we started he [Ryan] was on 16 exchanges a day and ... 81 units of MCT. And ... 6 of those 16 [exchanges] needed to be protein sources. (MCT)

The classical version of the diet was spoken about using ratios, the amount of fat to protein and carbohydrate, and the MAD and MCT diet were thought of in terms of exchanges or points relating to the different food sources (fat, protein and carbohydrate). This way of talking about food contrasts with Chowdhury *et al.*'s observation that:

Unlike nutritionists, human societies do not classify their foods in terms of vitamins, proteins, carbohydrates and so on, nor do they generally measure food consumption in terms of total calorie intake. (2000: 210)

Therefore, parents began to think similarly to nutritionists regarding their child's food intake, which differs from the way in which the majority of the population think about food. It is likely that speaking about food in these terms is a form of 'cultural health capital' (Shim, 2010) that parents had developed through their regular interactions with dieticians.

The extent to which parents were able to view food as medicine varied between families, but for many it was a practical way of overcoming some of the contradictions presented by the diet. Parents who were able to view food primarily as medicine were those who had been using the diet longest and those whose children were young or had co-morbidities or learning difficulties associated with their epilepsy. Some of the children's learning difficulties resulted in them not being particularly interested in food, which meant parents did not feel they were depriving their child of foodstuffs they wanted. Equally, children who were younger often did not compare their food to others' food consumption; this meant they did not feel they were missing out, which again meant parents did not regularly feel guilty when implementing the diet. Furthermore, the fact that those who had been using the diet longer were more likely to view food functionally suggests that this perspective may develop over time.

It has been noted that viewing food as medicine is common in some cultures (Helman, 2007). Often the perceived medicinal value of foods is a result of the meanings attached to foodstuffs, rather than in the substance of the food itself (Chowdhury *et al.*, 2000). In contrast to this, families using the ketogenic diet viewed food as medicine by drawing on the medical model (Bury, 2013) and, therefore, valued foods based on the substance of the food. This relates more to the contemporary interest in 'nutriceuticals' where foods and supplements are believed to treat or prevent particular illnesses (Helman, 2007; Will and Weiner, 2014). Although families viewing food as medicine is similar to this perspective, it differs because rather than specific foods, *all foods* the child consumed were seen to have medicinal value.

As a result of coming to view the child's food as medicine and by focusing on the purposeful aspect of the diet, a further new meaning was attached to the child's food – fat came to be seen as good, as we see below.

6.3.2 Fat as Good

Interestingly, despite the negative meanings that are normally attached to fat (Lupton and Chapman, 1995; Lupton, 1996, 2005; Counihan, 1999; Saguy, 2013) and the cultural importance placed on feeding children a healthy diet (Cook, 2009a, 2009b; Stapleton and Keenan, 2009), the high fat content of the diet was not something that parents found particularly problematic. Indeed, parents rarely mentioned the high fat content of the diet, unless it was in relation to the practicalities of incorporating the fat into foods and meals they were preparing. This unproblematic stance towards the high fat diet can be explained by the fact that parents started to view food as medicine and focused on the benefits this 'medicine' was having for their child; in doing so they were able to reverse the negative meanings attached to fat and fatty foods. During Jane's interview when she was speaking about choosing different products or brands she said, 'the more fat the better'. This is not a statement a parent would typically make in relation to their child's food consumption. However, it was echoed by a number of parents who said they checked product labels and searched out those with the highest fat content.

Similarly, two parents spoke to their children about 'the magic diet' and some siblings referred to the ketogenic diet in this way. In the extract below, Jessica is describing how the staff at her son's new primary school had told him not to drink the oil that was left when he had finished his salad.

He [Lukas] even told me that the other day he wanted to drink his salad sauce and then they said 'no, no, no. Just leave it'. So I'm going to have to tell them tomorrow 'no, that's the magic ingredient in that sauce'.

Again the term 'magic' is used in relation to the diet and, most importantly, the fat content of the food. This phrase was most commonly used to emphasise the positive impact of the diet, and particularly the high fat content, to children and those unfamiliar with it. However, it also illustrates the positivity with which parents viewed the diet as it was felt to have improved their child's quality of life to a far greater extent than other previous treatments. This positive view of fat explains why parents did not find implementing a high fat diet emotionally troubling; by seeing fat as good they felt that they were feeding their child 'good' foods. Indeed, a number of parents described the diet as healthy. For example, Ellen said:

I really do think it's a healthy diet. You're burning off fat quickly and you're getting the right amount of calories. It's weighed, it's to the gram. And she's [Faye's] getting a whole range. And she looks perfectly healthy on it.

The above discussion has illustrated that parents using the ketogenic diet came to see food as medicine and fat as good. However, some meanings usually attached to foods remained unchanged and the child's diet and food were manipulated in accordance with the associated norms. The first of these unaltered meanings is the focus of the following subsection.

6.3.3 Food as a Symbol of Inclusion

It has previously been argued that food is an important feature of family life as it symbolises cohesion (James *et al.*, 2009; Stapleton and Keenan, 2009). In this sense, food can be seen as a symbol of inclusion as sharing food and eating together signify membership or inclusion within a particular group. This meaning was consistently drawn upon by parents when discussing what their child ate, when they ate and with whom.

Special occasions or family events were common situations for parents to use food as a symbol of inclusion. For example, Jane created a ketogenic birthday party for her son where all the children were eating essentially the same foods. In other families, rather than being the same,

foods just had to have a similar appearance. For example, Hannah explained:

We went to my step-Mum's for Easter and she did a ketogenic meal ... It's egg whites all beaten up and that's his [Jack's]. And she puts some little berries on it. And it looks quite big on the plate and that's his pudding. So then everybody else had pavlova so it all looked the same colour. And actually he didn't really care what was on anybody else's plate, he was only interested in what was on his plate. But that would have been a coping strategy. And then the dinner itself, some of the kids didn't have starters so that wasn't a big deal. And then the main meal, his was all cut up and mixed up together, so was Alfie's [sibling's] so that's just how Granny did it for both of them.

As Hannah notes, using food as a symbol of inclusion was intended to include the child in events surrounding food in the same way as their siblings and/or peers. Furthermore, as in the extract above, using food as a symbol of inclusion was for practical purposes – ensuring the child ate their food without question – as well as emotional reasons.

Rather than foods just having a similar appearance, a further way of including children was to create ketogenic alternatives to the foods being consumed by others. Common alternatives that were made for the child on the diet included sweets, chocolate, cake and other foods that are usually seen as treats. For example, Hashani said:

Lately, because it's been the summer and her [Isuri's] sister has been having ice cream and lollies from the freezer I've started making her keto lollies, which she really likes. And again, they'll sit and have those together, which is really nice.

Significantly, as in Hashani's statement above, these alternatives tended to be given at times when siblings or peers were eating these foods. This meant that parents could feel they were treating children equally and the child on the diet was included.

In some instances, parents would make ketogenic alternatives to whole meals. A couple who went to great efforts to create alternatives to the

majority of their meals were Paul and Alison. They explained that they deemed this to be important so that their son felt included. On the evening of the interview Connor, who was on the diet, and his older brother Joel ate Bolognese together. Joel had pasta and Bolognese and Connor had meat and vegetables in a butter and tomato sauce. Importantly for this family, they referred to both meals as 'Bolognese'. Furthermore, some families also modified their food consumption and ate certain meals more frequently so the child on the diet could eat something similar. For instance, Rachel said:

We always used to have roast dinners because she [Daisy] could eat it. So she's gone off that, so that's a bit of a problem at the moment.

Therefore, as well as making ketogenic alternatives, parents sometimes choose to serve meals that they had alternatives to more regularly, again so the child was eating something similar to their family members. In Rachel's extract it can be seen that because her daughter no longer liked roast dinners she was struggling to find enough meal options that she had a ketogenic alternative to.

Not all families used ketogenic alternatives to include children in situations where food or a meal was a key feature; however, the majority did ensure children were included in another way. Although a discussion was presented above between Paul and Alison where they described not eating with their son due to feeling guilty when he started the diet, Alison went on to state, 'we've kind of got past that now'. Paul and Alison described how they felt it was important for them to move past the guilt they were feeling because it was vital that meal times were social times for their son. Indeed, these were the sentiments of the majority of the parents. For instance, children were never left to eat alone and, although Hashani's daughter often ate before the rest of her family, to ensure her meals were evenly spaced, she was still included in the evening family meal. Hashani explained:

We did try giving her [Isuri] food at the same time as us. She just plays with it and throws it around. So what we do, we'll give her

some salad or some vegetables so that she's at the table. Or even just an empty plate with a knife and fork. [Laughs] ... Yeah, she'll sit with us.

Many families still felt they were able to have family meals because they could eat together even if they were eating different foods. Alternatively, as in the example above, just the presence of family members was enough for some to consider the meal a social event in which everyone was included. This is in line with Gallegos *et al.* (2011) who found that people have different ideas about what constitutes a family meal. Additionally, parents' prioritisation of family meals reinforces the argument that parents still attach much significance to the 'family meal' (James *et al.*, 2009; Stapleton and Keenan, 2009).

However, parents did alter some norms surrounding eating practices. For example, family members did not share their food with the child on the diet. Equally, these children were taught not to share their food, as can be seen in the following extract.

Peter: There were little games that we played ... We made her [Faye] pancakes at breakfast and said 'oh, that looks lovely. Can I have some?' 'No. It's mine'. So that possessiveness about her diet ...

Ellen: It was *her* diet.

Peter: It was her diet. No one else could eat it.

Despite this alteration to eating practices, parents were still able to use food in other ways to ensure the child was included. Consequently, it has been illustrated that although food practices may have changed, the idea that food symbolised inclusion remained unchanged in families using the ketogenic diet. A further meaning that was not changed as a result of using the diet was that food was seen as a symbol of love.

6.3.4 *Food as a Symbol of Love*

Many of the decisions parents using the ketogenic diet made in relation to their child's food consumption involved prioritising either the child's enjoyment of food or larger portion sizes, both of which were ways of giving to children and using food to symbolise love.

There was no specific hierarchy between portion size and the child's enjoyment of their food; instead parents drew on these norms in different instances. For example, in the extract below, Kelly is explaining that she had made her son a ketogenic birthday cake but would not be doing so in the future because he was allowed such a small portion.

He's [Ryan's] always loved chocolate cake so we thought right, for his birthday last year we'd try that, and he did eat it but the amount he could have of the cake was, I don't know, the size of a small matchbox. It just was tiny ... it was about 2 or 3 exchanges for this tiny bit. Whereas, I said to my husband that he loves pears, he loves strawberries, you can get tons of pear and tons of strawberries for that. And you could put some cream on it. You could put sweetener in the cream.

Kelly initially drew on the norm related to showing love by providing children with foods they enjoy (Lupton, 1996; Kaplan, 2000); she describes how for her son's birthday, an occasion associated with treating children, she tried to replicate a type of cake that her son had always enjoyed. However, Kelly justified her choice of not repeating this in future by drawing on portion size instead. This discursive reasoning is similar to the reconciliation of repertoires described by Will and Weiner (2014). In their research on cholesterol-lowering foods they found that people drew on the repertoires of health, pleasure, sociality and pragmatism when speaking about their food choices. Drawing on these categories, here the discussion of norms relating to portion size and the child's enjoyment of food both relate to the repertoire of pleasure; however, they appear to constitute separate and distinct repertoires in this context.

Small portion sizes were something that parents often tried to compensate for in different ways. For example, Jessica said, 'we have these tiny dishes that make it look like a lot'. Additionally, similarly to Kelly's explanation of food choice above, many parents talked about how they would choose one food over another because it gave the appearance that it was a larger portion.

However, portion size was not always given priority when parents made choices associated with the child's food consumption. In the extract below Kelly is explaining why she opted for her son to go on the MCT diet over the classical version of the diet.

In general as he's [Ryan's] got a bit older he enjoys food. So I didn't want to take that away from him and I wanted to keep him eating things that he enjoyed eating, even if it was less.

Here Kelly prioritises feeding her son food he enjoys over portion size. In this instance, therefore, she has reversed her prioritisation of the same two norms when compared to her previous discussion about birthday cake. Similarly, Hashani drew on the importance of providing children with food they enjoy when she commented that her daughter's meals are 'quite samey, but she [Isuri] really likes pizza so it's all right'. Rather than portion size or the child consuming a varied diet, here the child's enjoyment of food is given priority.

Equally, the ketogenic alternatives that parents created, described above, illustrate that parents were trying to give children food that they enjoyed. A further way of ensuring children were eating foods they enjoyed was to give them choice over their food consumption. For example, Jane said:

I do tend to give him [Toby] quite a choice a lot of the time and say 'look, we're having this. What do you want?' Because I think he should have a bit of a choice really because he doesn't have a lot.

In one instance this made the diet appealing to a sibling; Ana noted that ‘at one point in time he [Ivan] also wanted to be on a diet because he saw we were trying our best to satisfy Stefan’s requests for food’. This extract shows that parents sometimes gave the child on the diet more choice than siblings were afforded in order to make up for the foods they could not have and ensure their happiness.

This subsection has illustrated that, at times, parents drew on cultural food norms relating to portion size and feeding children foods they enjoy in order to justify the food choices they had made. By prioritising these different norms parents were using the child’s food as a symbol of love to show that they cared for them. Furthermore, parents themselves could still feel that they were providing their children with love. There were two further meanings that applied to the ketogenic diet, which were also attached to medications; these two meanings are the focus of the next section.

6.4 Meanings Attached to Medications and Dietary Treatment

This section focuses on meanings that were attributed to more than one form of treatment. The first subsection deals with the ways in which some children viewed their daily medications; the opinions of parents regarding how they thought their children felt about their treatments are also drawn upon.

6.4.1 Treatment as a Symbol of Difference

One of the meanings attached to medications by seven of the 10 children was that they felt their AEDs marked them out as different from their peers or siblings. For five of the children this sense of difference was negative and, as a result, they were reluctant to take their medication in the presence of others. However, two children felt that this difference gave them additional status or a sense of achievement.

Revealingly, the majority of children who perceived their treatment to be a symbol of difference in a negative sense did not explicitly speak about their medication in this way. This may have been because children who felt different as a result of the condition were reluctant to express such feelings and, in fact, also avoided talking about epilepsy more generally. Instead, evidence that certain children viewed their medication negatively was gleaned from other family members, particularly parents. For instance, as Emma, Tom's mother, explained 'he won't take tablets in front of anybody'. Emma described that on holidays, days out or school trips Tom would not take his AEDs publicly; consequently, Emma would find a secluded or private place for Tom take his medication. Emma believed that Tom felt different as a result of his condition, which was illustrated in Chapter Five, and this was why he was reluctant to take his medication in front of others. Indeed, Emma thought Tom felt that taking his medication publicly would draw attention to his epilepsy, which supports Goffman's (1963) argument that medications can be stigma symbols.

Tom (9) spoke little about his AEDs during his interview. For instance, when asked to talk about a photograph of his tablets, he stated the time at which he took his medication daily and then added 'sometimes I have Calpol before I go to bed'. However, Calpol was not shown in the photograph. One explanation for Tom's response is that he misunderstood the nature of the question and thought the researcher was enquiring about his medication use generally, rather than his epilepsy medication specifically. However, Tom's response may instead be evidence that he viewed his AEDs as a negative symbol of difference, as he preferred to talk about Calpol, which he saw as a 'normal' medication. Calpol may have been seen to be a symbol of normality because of its widespread use amongst children, in contrast to AEDs.

Furthermore, Tom's family had been offered the ketogenic diet and Emma was keen to try it, but Tom made the decision that he did not want to.

Emma: We did try and sort of talk to him about it and how it would help but he just said he wanted to take tablets. And he was fully aware that he would still have breakthrough seizures like he does, but that's what he wanted to do ... He's different enough as it is. Do I want to make him look even more different by making him eat these weird and wonderful things at school? As well as at home, having different meals with us. I think that was part of Tom's decision as well. It's not just the fat, it's different.

I: OK, he just wanted to be the same as everyone else?

Emma: Yeah. He doesn't want to be different at all.

Tom may have made his decision based on his taste preferences. However, Emma was sure that he also felt that eating alternative foods would have been viewed as a symbol of difference by others, and that the ketogenic diet would have been less easy to conceal than medication use. It seemed that although Emma was eager to try the diet she also agreed that this treatment would make Tom appear different to others. Indeed, James (1993) found that alternative food consumption can lead to children being teased by their peers. Consequently, although Tom felt his medications marked him out as different to others, he also felt these were easier to hide, and were, therefore, preferable to dietary treatment.

Similarly to Tom's preference for AEDs over the ketogenic diet, some families expressed a preference for particular forms of medication. Below Anita is speaking about her daughter's AEDs, which she took in granule form.

It is easy because you can just put a couple in your bag or, you know, if she's [Lydia's] going to a friend's she can do it quite discreetly. She hasn't got to [measure out the liquid medication in a syringe], you know, so it's quite good.

Tablets tended to be viewed as preferential to liquids for practical reasons because they were easier to transport and administer outside the home. In some instances they were also viewed as more favourable because, as Anita explained above, they could be taken discreetly and without the need to use a syringe to measure or dispense the medication. In this sense, tablets and,

in some instances, granules were valued because they allowed treatment to be kept private. This is similar to van der Geest's (2010) and van der Geest and Whyte's (1989) argument that medications are popular because they are more private than alternative forms of treatment; however, it differs because in this instance certain forms of medication were preferred to others for this reason.

Although Tom believed that the ketogenic diet would attract negative attention from others, no parents of children on the diet reported that others had treated their children negatively as a result of dietary treatment. In fact, although the child's food was seen to be different, this gave it positive or 'special' qualities in the eyes of some children. Rachel recalled that when her daughter Daisy's class had done baking at school and made ketogenic coconut cookies, many children had come out of school at the end of the day saying 'we had a Daisy biscuit'. Similarly, Jane explained that:

He's [Toby's] got a little friend that comes round for tea. And we freeze jelly and he has jelly sweets. And although Toby doesn't like the jelly anymore, he likes the jelly sweets. And his friend's so excited when he comes here, to have one of Toby's jelly sweets.

It is not possible to know for certain, without asking the children themselves, whether they felt their diets were a symbol of difference and, if so, whether they saw this to be a positive or negative difference. However, based on the parents' interviews it is likely that some children, at times, felt positively about eating different food to others. For example, Ellen said 'it [the diet] was special. It was actually special to her [Faye]. It was hers'.

Similarly to the way in which parents felt children on the diet viewed their treatment positively, two children felt their AEDs differentiated themselves from others in a positive way. This attribution of positive difference related to the form the medication took, with tablets being seen, in some instances, to elevate their status. For instance, Nicola said:

Literally in the whole time he's [Zak's] been taking the tablets we've had one that didn't quite go down properly. I think he was showing off about how good he was at doing it.

The above extract demonstrates Zak's sense of achievement, as he was keen to display his ability to his family members. This may be because Zak (13) originally had difficulty swallowing tablets. In this instance, therefore, rather than a stigma symbol, medications were viewed as status symbols.

Max (7) was also proud of his ability to take tablets and often expressed this to those outside the family as well. It seems that Max felt proud of taking his tablets because he was able to do something that his sibling or peers could not. For instance, his mum, Kate, explained:

He's [Max's] just chuffed to bits, because the size of the tablet he takes is bigger than what Amelia [sibling] could manage. If Amelia has a paracetamol she has to have it in two halves. So he's pleased as punch and he tells everybody about that as well.

Max supported Kate's statement in the group interview when he brought up the topic of the size of his tablets.

Max: Oh, and you won't believe how big, how much medicine I have to have per day.
I: How much medicine do you have to have?
Max: One thousand milligram tablets.
Kate: A thousand milligrams now, isn't it?
Max: Tablet form.
I: Oh, do you have tablets?
Max: Yep.
Kate: Yeah, that's new.
Max: And I swallow them on my first go!
I: Do you?
Max: Yep.
I: Wow, you're better than me. I'm not very good at taking tablets.
Max: I am!

This interaction with Max can be contrasted to Tom who said little about his medication, which suggests that some children held opposing views with regard to their treatment. Max's sense of achievement may be attributable to Whyte *et al.*'s (2002) finding that different forms of medication carry

different meanings, with tablets being seen as adult medications and syrups being seen as appropriate for children. Some children, therefore, may see tablets as a means of gaining access to the adult world and a higher status. It has previously been found that children administering their own medication can gain status with their peers as it denotes responsibility (Christensen, 1998); however, in this instance medication as a status symbol was primarily the result of the form and size of the medication. Building on the positive meanings attached to treatments, the next subsection focuses on the perspective of treatment as a saviour.

6.4.2 Treatment as a Saviour

All three forms of household treatment discussed in this chapter were, at times, seen as a saviour. In a very literal sense, some treatments were seen as a way of saving the child's life. This most commonly applied to emergency medications, and the fact that these treatments are referred to as 'emergency' or 'rescue' medications clearly links to the idea of these treatments being saviours.

However, emergency medications were not always immediately viewed in this way, as Steve explained:

When we were first given it I always likened it to driving a car with an airbag. You know, we had it for over a year, and you drive around in this car never knowing if the airbag would deploy if you needed it. And of course when we did administer it, we gave it to him [Zak] and within 2, 3 minutes he was back. And it was such a relief to think we didn't have to live on that knife-edge all the time. And we now actually know that this magical stuff can go in his mouth and he'll be out of it [the seizure].

Here Steve refers to living on a 'knife-edge' and the relief that this 'magical' medication was effective. This perspective is comparable to those who view treatment as a 'magic elixir' (Shoemaker and Ramalho de Oliveira, 2008). However, the parents who viewed emergency medications as a saviour can be contrasted to Catherine, quoted previously, who saw her daughter's

emergency medication as an unpleasant necessity. Nevertheless, seeing emergency medications as a saviour was a more common view, as parents in nine of the 11 families, where these drugs had been prescribed, viewed them in this way.

Emergency medications were not the only treatment to be viewed as a saviour. One family stood out from the others because they also viewed daily AEDs in a similar way. The parents in this family saw seizures as a threat to the child's life and AEDs were seen as the primary way of preventing seizures. Consequently, as can be seen in the extract below, as well as a preventative measure, AEDs were also viewed as a saviour.

Steve: And that was always a comfort to us because we knew just before bed, an hour before bed he [Zak] was being pumped full of drugs so we knew that the likelihood was that he wasn't going to have a fit at night. And again, we read about, what's it called? Night epilepsy syndrome, or whatever, and that scares the life out of both Nicola and I ...

Nicola: He's talking about SUDEP. Sudden death through epilepsy.

Steve: Sudden death at night, yeah. But that scares the life out of me. But with the liquid inside him, brand new in his system, we knew that that was very unlikely to affect [him] because he was so full of drugs.

Here Steve's fear of SUDEP is offset by his son being 'pumped full of drugs' that he believed would prevent Zak having a seizure.

In his interview Zak (13) also expressed a similar view, as the following extract illustrates.

I think there was one point where I was first getting onto the medicine two years ago and my dad sent me a text like just as I was coming out of school and said 'you forgot to take your medicine'. I was surprised I survived the day.

Zak talked a number of times about epilepsy being a threat to his life, as was noted in Chapters Four and Five, and this extract shows that he saw his AEDs as a way of preventing his seizures. Zak expresses his shock that he

'survived' without his medication, which again links to the idea of treatment being seen as a saviour. This is in line with previous research that found that the perception of a condition as debilitating and a medication as having high efficacy led to individuals feeling 'safer' as a result of treatment (Webster *et al.*, 2009).

The reason that only one family saw AEDs as a saviour may be because this family had gone through a particularly stressful experience when Zak's first seizure resulted in him being admitted to intensive care. Consequently, this family overwhelmingly saw epilepsy as a threat to the child's life. Some of the other parents also saw this as a possibility, but either the child's condition had progressed more slowly, or the child had been diagnosed longer and parents had had substantially more time to come to terms with this possibility. The nature of the child's condition, experiences at onset, and length of diagnosis may, therefore, have all contributed to this family viewing AEDs as a saviour.

The third form of treatment that was viewed as a saviour was the ketogenic diet. For six of the 10 families using the diet, a reduction in seizures and emergency hospital admissions meant that this treatment was seen, again in a literal sense, as a lifesaver. For instance, Naomi said:

We have seen a significant improvement. In fact, September this year we will have been two years out of hospital ... Unfortunately we're not one of the small few for who it completely stops the seizures, but it's given me back my daughter [Maisie] without a doubt.

For Naomi, and others in a similar situation, success on the ketogenic diet meant that they had gone from regular emergency admissions to hospital to few or none. This treatment, therefore, was not only a saviour of the child's life but also for the family as a whole who no longer, or very rarely, had to go through the process of seeing their child or sibling admitted to hospital. The diet, consequently, provided a form of stability for these families.

In Naomi's extract above she talks about getting her daughter 'back'. This same feeling was expressed by a further three parents. Some felt regaining their child was a result of a reduction in AED treatment, whereas others felt it was attributable to the diet itself, as Hannah explained:

The diet hasn't given us seizure freedom or much control really. The drugs are still controlling it to a certain extent. But the diet has given us Jack's personality. Jack is much clearer in his thinking and himself. It's like we've got his little personality back.

For these families the diet was again seen as a saviour, as they felt they had regained the child's personality, which was previously seen to be lost.

Two additional parents, however, did not feel they had regained their child, but rather that they had seen them for the first time. For instance, Hashani said 'it's like somebody reached in and switched her [Isuri] on'. Similarly, Kelly commented 'it's like having a child that was running on 10% now running on like 80, 85%'. Therefore, like the parents above, Hashani and Kelly felt that they had been able to access elements of their children's personalities that had previously been lost. All the parents who expressed sentiments of regaining their child or seeing their personality for the first time, also spoke about what this meant for the child; they all felt that their children were happier as they were more able to participate in activities because they experienced fewer debilitating side effects from the condition and/or drug treatments.

6.5 Conclusion

This chapter has explored the meanings attached to three household treatments for childhood epilepsy – AEDs, emergency medications and the ketogenic diet. In doing so, the research question regarding family members' views of medications has been answered. Indeed, the differences between parents' and children's perspectives have been outlined and discussed. Furthermore, it has been illustrated that some meanings applied only to medications, some were only associated with ketogenic foods and

other meanings were attached to both drug and dietary treatments. Consequently, the research question relating to the meanings attached to foods when implementing the ketogenic diet has also been addressed.

It has been suggested that, particularly among parents, daily medications are not administered without reluctance. When discussing their child's AEDs many parents spoke about the side effects they perceived the child's treatment to be having and the possibility of long-term effects. This is in line with previous research that has found that there is resistance to medication use (Gabe and Lipshitz-Pillips, 1982; Britten, 1996; Whyte *et al.*, 2002; Pound *et al.*, 2005; Chamberlain *et al.*, 2011). As a result of negative associations with medications many parents saw treatment as an unpleasant necessity in that it was disliked but necessary in order to control or reduce their child's seizures.

However, 15 families held overwhelmingly positive views of particular treatments and saw them as a saviour. This meaning was particularly applied to emergency medications and the ketogenic diet, as these treatments were seen as a way of saving the child's life. The ketogenic diet was also viewed in this way because it was seen to have positive effects on the child and many parents described (re)gaining aspects of their child's personality.

It has previously been argued that children's experiences are not synonymous with those of their parents (Christensen, 1998). This was particularly highlighted here in relation to children's experiences of epilepsy treatments. Although children saw medications as an unpleasant necessity, similarly to their parents, children's negative associations with their medications differed to those of their parents. The children primarily viewed treatments negatively as a result of the taste of medications, rather than due to side effects. Furthermore, there was evidence to suggest that the meanings some children associated with medications changed over the course of treatment to incorporate the condition's chronic nature. Indeed,

children came to see medication as a preventative measure rather than a cure.

Additionally, it was mainly children's views, or parents' interpretations of their thoughts, which related to treatment as a symbol of difference. Some children saw treatment as a symbol of difference in a negative sense, similarly to Goffman's (1963) argument regarding stigma symbols. However, other children viewed medications as a symbol of difference in a positive sense; they felt that their ability to take their medications gave them additional status and/or a sense of achievement.

Furthermore, the findings presented above support the fundamental argument in the sociology of food literature that food has intrinsic social and cultural functions and meanings attached to it (Beardsworth and Keil, 1997; Counihan, 1999). Despite the nature of the ketogenic diet, food was still seen to symbolise inclusion and love. In line with the existing literature, parents placed considerable emphasis on the family meal (James *et al.*, 2009; Stapleton and Keenan, 2009) and often used ketogenic alternatives to include children in different situations. Parents also drew on food norms related to portion size and showing children love by providing them with food they enjoy (Lupton, 1996; Kaplan, 2000) so as to compensate for the foods they were no longer allowed to consume.

However, it has also been shown within this chapter that although the meanings attached to foods are ingrained and difficult to challenge, they are not fixed. By coming to view food as medicine parents were able to reverse the negative meanings attached to fat. It could be argued that this potentially was one of the most difficult food norms to alter given the current, and prolonged, emphasis on reducing dietary fat in health campaigns (Mennell *et al.*, 1992; Blank *et al.*, 2009). By viewing food functionally parents removed many of the cultural layers normally afforded to food, suggesting that the meanings attached to foods are malleable and may be altered if used as a medical treatment. As was the case in this study,

the meanings attached to food may be more likely to be altered if dietary treatment is more successful than previous treatments.

This research has also added a new dimension to the literature relating to how families manage dietary change for medical reasons. Previous studies found that when one family member had been recommended dietary alterations for medical reasons, other family members often made the same changes (Kelleher, 1988; Maclean, 1991; Gregory, 2005; Pitchforth *et al.*, 2011). Although, to an extent, the same was found here – parents sometimes chose not to eat particular foods in front of the child on the diet or served certain meals more regularly – it has also been shown that family members are not always able to adjust their food consumption in line with the recommended diet. Indeed, it was found that when parents were unable to take on the same dietary alterations, many used other techniques to adapt to these changes. For instance, families were able to create ketogenic alternatives of the foods being consumed by others. This creativity with food shows that the diet may be manipulated to fit in with family members' consumption patterns, as well as others' food consumption being altered to suit the diet. Furthermore, in contrast to Veen *et al.*'s (2013) research, the diet was not demedicalised; in fact parents drew heavily on the medical model in their explanations of the diet and food choice. The ways in which families adapt to dietary changes, therefore, may vary depending on the nature of the diet.

Overall, it has been shown that children with epilepsy and their parents attached a variety of meanings to household medications for childhood epilepsy. At times their views aligned, but it was also found that there were significant differences between the perspectives of the children and their parents. Furthermore, this is the first study to have explored use of the ketogenic diet from a sociological perspective. The focus of the chapter that follows is how epilepsy impacted on 'doing family' and, in part, how some of the risk management strategies described in Chapter Five affected family relationships.

Chapter Seven: Doing Family in the Context of Childhood Epilepsy

7.1 Introduction

Doing family in the context of childhood epilepsy is explored within this chapter by examining how the condition affected family practices and family relationships. Initially, the focus is on how the risk management strategies, described in Chapter Five, influenced family members' interactions with one another and how they perceived changes to their interactions to have impacted on their relationships. Through such analysis, the following research question is addressed: How does childhood epilepsy affect family relationships? Attention then shifts to the ways in which siblings helped to manage their brother or sister's condition on a daily basis. In particular, the caring roles taken on by siblings are outlined. Consequently, the following research question will also be answered: To what extent do siblings contribute to informal care practices associated with their brother or sister's epilepsy?

Morgan's (1996) influential 'family practices' concept is used as a framework in this chapter. He argued that the family is not a static structure, but rather is defined by family practices – the everyday interactions and activities between those who are defined as family members by any given individual. Previous research has shown that having a family member with a chronic condition can influence families' activity participation (Nocon and Booth, 1990; Kelly, 1992; Hill and Zimmerman, 1995; Prout *et al.*, 1999; Barlow and Ellard, 2006; Timmermans and Freidin, 2007). However, there is less research detailing how chronic illness can affect everyday interactions or the ways in which family members perceive their relationships with one another (see Scambler 1983, 1989 for a discussion of conflict between spouses and young adults and their family members as a result of epilepsy). Of particular interest, therefore, is the extent to which childhood epilepsy influenced family practices and,

consequently, what this meant for family relationships. This analysis will help to deepen understanding about the experiences of families where one family member has a chronic condition by moving beyond a description of altered activities and exploring what this meant for the way in which individuals 'do' family.

Furthermore, there is a limited amount of research that has explored siblings' childhood experiences of having a brother or sister with a chronic condition. Two exceptions are Dixon-Woods *et al.* (2005), who looked at families with a child with cancer, and the work of Bluebond-Langer (1991), who focused on families with a child with cystic fibrosis. Both detailed the negative implications of having a brother or sister with a chronic condition on siblings. For instance, Bluebond-Langer (1991) described how siblings often felt jealous of the attention the ill child received, which has also been described by parents of children with other chronic conditions (Nocon and Booth, 1990; Barlow and Ellard, 2006). However, these researchers have not addressed how these emotional responses impacted on the parent-sibling relationship. Drawing on the sociology of emotions, where it is argued that emotions are, in part, shaped by social and cultural forces (Hochschild, 1998; Williams and Bendelow, 1998; Barbalet, 2002), the findings presented within this chapter will build on the work cited above by exploring the experience of siblings of a child with epilepsy. It is intended that this work will provide an insight into how siblings' experiences of a chronic childhood condition can affect family relationships.

There is, however, another side to the sibling relationship; the caring element is also a defining feature of siblings' interactions and relationships with one another (Edwards *et al.*, 2005; Mauthner, 2005; Sarre, 2010). There has been some interest in the care work children engage in; certain researchers have looked at siblings who 'babysit' for younger brothers and sisters (Weisner and Gallimore, 1977; Kosonen, 1996; Morrow, 2008) and others have focused on children who are officially defined as 'young carers'

(Aldridge and Becker, 1993; Frank, 2002; Underdown, 2002; Dearden and Becker, 2004; Warren, 2007; Aldridge, 2008; Smyth *et al.*, 2011; Wihstutz, 2011). Despite this, the ways in which chronic illness influences the caring side of the sibling relationship has received little attention from a sociological perspective. Furthermore, much of the research on young carers is policy focused and where caring for siblings, rather than parents, is mentioned, it has not been explored in depth. Moreover, there is a lack of research on children who provide care for family members but are not officially recognised as young carers. Consequently, it is intended that the findings presented within this chapter will help to expand knowledge on children who provide informal care by looking at the care work/roles that siblings took on in families with a child with epilepsy. It is hoped that this approach will offer a more rounded overview of siblings' experiences by moving beyond the purely negative influence that having a brother or sister with a chronic condition can have on siblings.

The chapter begins with an exploration of the idea of relationship intensification with regard to the parent-child (with epilepsy) relationship (referred to as the parent-child relationship from now on) and particularly siblings' reactions to this. Following on from this, the different caring roles that siblings took on are defined and the ways in which socio-demographic characteristics influenced siblings' caring roles will be outlined.

7.2 Parent-Child Relationship Intensification

It was found that the parent-child relationship was intensified at times in all the families that participated in the study. Here intensification in the relationship meant that parents and children with epilepsy spent more time in one another's company and in closer proximity to each other than may have been anticipated for the child's age. This additional time together was primarily the result of parents' manipulation of space in response to their perceptions of the physical risks resulting from the child's condition, which was discussed in Chapter Five. At times when the parent-child relationship

was intensified, family practices were altered as parents and children spent more time together. It was demonstrated in Chapter Five that the children with epilepsy either were not aware of this adjustment or did not find it problematic. However, parents in 10 of the 23 families found relationship intensification challenging, either during times of tension in the parent-child relationship or because they felt these altered family practices did, or might, impact on their time with other family members.

One parent in particular felt relationship intensification could be problematic for the parent-child relationship; however, her husband was keen to contest the idea that there was any heightened tension in this relationship, as can be seen in the extract below.

Nicola: The only other thing I think which does have an impact ... is that actually we spend very little time apart from Zak. He doesn't even have the bus journey home from school to clear his head of what's happened at school or to do anything. So there's very little space in our relationships, isn't there? Because the nature of it is that he's essentially got one of us with him the whole time ... I just think by being together all the time if there's any tension in the relationship that's just going to escalate. So I do think that has an impact, not huge, but that there isn't much space for anybody ... So I think that does have an impact on our relationships when there's a bit of a strain.

Steve: But we all get on very well.

Nicola: Yeah, but it is that, there isn't that real...

Steve: And it's not that there's a strain there ... I mean yeah we have an irate moment over homework or there's a, you know, 'haven't you cleaned your room?' But that's just normal.

...

Nicola: But ... actually there isn't any free, free time ... Which must drive him mad as well. Sometimes it drives me mad and I think 'ah, if you could just walk down the road for five minutes or something' ... I definitely feel there's, you know, that always with each other kind of thing.

Although Nicola and Steve disagreed somewhat regarding the effect of relationship intensification, they did both agree that they spent more time with their son than they would have done if he did not have epilepsy. It may

be that Nicola felt this was more of a problem than Steve because Steve worked full-time and it was usually Nicola who spent the most time with their son during the week.

As Nicola was the only parent to suggest that tension in the parent-child relationship may be heightened at times due to this additional time spent in one another's company, it may be that the age of the child had a bearing on how parents felt. Indeed, Zak (13) was the oldest child in the study who had epilepsy. Furthermore, parents tend to share a number of common understandings: that children will generally become more independent as they get older (Brannen *et al.*, 1994; Jackson and Scott, 1999; Backett-Milburn and Harden, 2004); that teenagers are more rebellious or ruder than younger children (Brannen *et al.*, 1994; Sarre, 2010); and that relationships between children and parents tend to be renegotiated during adolescence (Brannen *et al.*, 1994; Gabb, 2008; Sarre, 2010). Consequently, it may be that relationship intensification, in response to the condition, is most likely to be problematic for parents during the child's teenage years when it is expected that there will be more conflict in the parent-child relationship and that children will spend less time under parental supervision.

More commonly, parents felt intensification in the parent-child relationship impacted on their practices with other family members. For example, Hannah commented:

He's [Jack's] constant one-to-one, which is really hard when you're a Mummy of four kids. That's your second child, who should be independent, has to have one-to-one and you've still got a two-year-old and a one-year-old.

This extract illustrates that Hannah's family practices had been disrupted as a result of childhood epilepsy. Similarly to Hannah, those who made comparable comments were those who supervised their child the majority, or all, of the time.

The children with epilepsy were less likely to comment on alterations to family practices with their parents. Despite Nicola and Steve both feeling that they spent more time with their son than they may have otherwise done, Zak did not feel his relationship with his parents had changed since being diagnosed two years previously. For example, when asked if his epilepsy had altered his family relationships, Zak (13) replied 'obviously the relationships are still the same meaning that my Mum's my Mum and obviously like that'. In fact, the only child to speak specifically about disrupted family practices was Harry (8), who said he felt guilty for disturbing his parents during the night, as can be seen below.

Harry: When I'm having my epilepsy tablets, if I don't have them without having something to eat then I'll go really sick and have bad nightmares [seizures] and make my Mum and Dad have an awful night. Which I don't feel happy about.

I: So you don't like it when you wake them up or they don't sleep very well because you've had a bad night?

Harry: They'll all be grumpy in the morning because they're tired.

Here, Harry felt altered family practices were a result of his symptoms, rather than increased supervision.

Although Harry was the only child to speak about his symptoms impacting on others, below Carol, Rosie's mum, describes an incident when Rosie had been upset because she had hit Carol during the night when she was having a seizure.

I can remember sort of going 'oow' and she [Rosie] must have been at the end of it and she said 'sorry mummy' and got really upset. And I was like 'it don't matter Rosie. It don't matter'. And I sort of got up and got a bit of tissue and she saw me and she got all upset because my mouth was bleeding. But I said to her 'it's all right. You can't help it. It doesn't matter. Don't worry about it'. But, you know, she's a worrier and she kept going on about my mouth.

Based on the extracts above it seems that the children were most likely to feel guilty about the impact their seizures had on their parents, rather than the additional time spent together in response to their parents' perceptions

of physical risks. Indeed, as was demonstrated in Chapter Five, none of the children commented negatively regarding increased levels of supervision.

Although the children with epilepsy did not appear to feel their relationships with their parents had been intensified as a result of their condition, siblings were much more likely to perceive this to be the case. Siblings' perceptions of the parent-child relationship and their responses to intensification within this relationship are discussed below.

7.3 Siblings' Responses to the Intensified Parent-Child Relationship

Five of the 11 siblings who were asked about family practices commented on their brother or sister with epilepsy receiving additional attention from their parents. Moreover, three of these siblings talked about feeling 'left out' as a result of this alteration to family practices. Furthermore, parents in eight of the 23 families thought siblings felt 'hard done by' and in three of these eight families parents also believed that these feelings had led to conflict in the sibling relationship or the parent-sibling relationship. Consequently, in these instances the siblings and/or parents perceived relationships within their families to have changed as a result of altered family practices.

7.3.1 Feeling 'left out'

As was discussed above, some of the parents felt there was the potential for siblings to feel left out due to the amount of time they spent with the child with epilepsy. Indeed, three siblings sometimes did feel this way, or said they had in the past. For example, Logan (7) said 'I don't like it when he [Dylan] gets all the attention'. Similarly, Zoe (16) commented that she felt left out around the time when her sister's seizures began:

It's just like, I think I worried about her [Rosie] a lot and then I just felt a bit left out in a way. I know like because she was ill, I

didn't really want to sound selfish. But I was still 13, 14, I think it was, yeah, and I just felt a little bit pushed out the way.

Drawing on the sociology of emotions (Hochschild, 1998; Williams and Bendelow, 1998; Barbalet, 2002) it can be seen that Zoe's emotional response to these altered family practices was in part a product of her social circumstances. It seemed siblings tended to notice intensification in the parent-child relationship, which meant that they felt they were no longer receiving the same treatment or amount of attention as their brother or sister. Consequently, in these instances, siblings felt their place within the family had changed somewhat – they no longer felt equal to their brother or sister. Therefore, similarly to previous studies (Bluebond-Langer, 1991; Dixon-Woods *et al.*, 2005), it appears that having a child with a chronic condition can lead to some siblings feeling left out. However, not all children in this study described feeling this way; possible reasons for this will be explored later on.

Parents were aware of the way siblings might feel as a result of changes to family practices and sometimes thought that having a child with a chronic illness that needed additional attention made parenting difficult. For example, Ruth thought her youngest daughter, Gemma, often felt left out as a result of her sister's epilepsy, as can be seen in the extract below.

She [Gemma] knows that one of us is with her sister [Alice] and she's very very jealous of that. Not in a bad way but, you know, that's what she's known her whole life so it's not even really jealousy, it's just, erm, a lack of understanding that somebody wouldn't be with her.

Ruth's extract illustrates Hochschild's (1998) argument that we each have an 'emotional dictionary' that defines what emotions are; Ruth originally defines her daughter as 'very very jealous', but then goes on to explain she does not feel this is the best description of her daughter's emotional response and struggles to find an adequate explanation from her emotional dictionary. Although Ruth commended that the intensified parent-child relationship had been consistent throughout Gemma's life, younger children

often spend more time with their parents and it may have been that as Gemma started to grow older she noticed she was receiving less attention but her older sister was still getting the same amount. During Gemma's interview she responded 'don't know' to every question relating to her sister's epilepsy. This may have been because, as her mother suspected, she did feel left out because of the intensified parent-child relationship and, therefore, did not want to talk about her sister's condition.

Despite parents often interpreting siblings' behaviours as being a result of jealousy, one sibling thought this interpretation was unjust. Indeed, Natalie (14) talked about when she discovered that her sister, Lydia, had stopped taking her tablets, but her parents thought she had hidden Lydia's tablets in order to get her into trouble.

Natalie: I found it [the tablets], but they thought I was hiding them.

I: Who did?

Natalie: My parents. Because I think it was an attention thing, they thought I wasn't, like I didn't like her [Lydia] getting all the attention. But no, I'm not really that bothered.

During their group interview Natalie's mum, Anita, said Natalie often said Lydia was 'favouratised' because of her epilepsy. Like some of the parents, Natalie appeared to feel that this additional attention was an inevitable result of her sister's condition; when asked if she felt her parents ever favoured Lydia over her, she replied:

Probably. But they wouldn't say it. But it's the kind of thing that if someone's got something, say like that [epilepsy], like an illness or something, it always happens because it affects her [Lydia] more than it affects anyone else. So like they [parents] have to be more positive or more, like do stuff with her and stuff because it's taken a bit of time for her to get used to it and stuff.

Based on Natalie's and Anita's comments it is hard to ascertain Natalie's true feelings regarding intensification in the parent-child relationship. It has previously been argued that each individual has an 'emotional bible', which defines what should, and equally should not, be felt in a given context

(Hochschild, 1998) and that children are taught to control their emotions and only express those emotions that are socially acceptable (Mayall, 1998). Consequently, a possible explanation regarding the above extract is that Natalie felt this was the socially acceptable response to give as she did not want to portray herself as jealous.

Whether or not siblings did in fact feel left out, parents sometimes thought that they did and also felt that this led to conflict between themselves and the sibling and/or between the sibling and the child with epilepsy, as we see below.

7.3.2 Sibling-Parent Conflict

In two of the families one or more family members spoke about how they thought the child feeling left out resulted in conflict between the sibling and their parents. Within both these families it seemed that perceptions of conflict between siblings and parents fluctuated; in one family this conflict tended to occur around the child's seizure occurrence, and in the other it was a more ongoing conflict that came to the fore when the sibling perceived that his brother was allowed to behave inappropriately without being told off due to his condition.

Although Nicola and Steve did not necessarily agree on how to describe their daughter's conduct, they did agree that around the time of Zak's seizures, Chloe would display 'attention seeking' behaviour. For instance, the following interaction occurred during their interview:

Nicola: We get a bit of kickback afterwards, don't we? We get a little bit after he's [Zak's] had one [a seizure], not a lot.

Steve: No, I think...

Nicola: After he's had one.

Steve: It's not kickback, that's the wrong word.

Nicola: No. But after he's had one there's that element of...

Steve: 'Why's all the attention on him?'

Nicola: Yeah, there's a bit of attention seeking and we've had the occasional 'nobody cares about me'.

...

Steve: But, as you say, sometimes afterwards, or at the time, I mean we've had paramedics in here and she'll [Chloe] come out and say 'Daddy, daddy, where's my, do you know where my colouring book is?' And it's kind of like a 'me as well! Me!'

Nicola and Steve used their 'emotional dictionary' (Hochschild, 1998) to define Chloe's response and explained that she sometimes reacted in this way due to a combination of her not understanding what was happening and also being fearful of the situation.

However, Nicola explained that Chloe's reactions sometimes caused tension in her relationship with her daughter:

When he'd [Zak] had the two [seizures] at school that day and he didn't go to school the next day, she was not very nice that evening. And actually, when I put her to bed, when push came to shove it was 'Zak hadn't been to school today, it's not fair. I'd had to go to school'. But the way she got round to saying that, actually was by really quite horrible, not nice behaviour ... So actually, it ended up with me getting really cross. And actually then at bedtime when I said to her 'why have you been like this?' When it came out there was a big thing about the fact that she'd had to go to school and Zak had had a day off.

In this instance it seems that Chloe felt Zak had been favoured by their parents and she was consequently annoyed with them. However, Chloe did not speak about feeling this way in her interview. Yet, this may have been because these feelings were not at the forefront of her mind because, as Nicola and Steve explained, she tended to behave in this way immediately after her brother had a seizure. Although Chloe did not say she felt this way, Steve and Nicola certainly felt their son's epilepsy periodically affected their relationship with their daughter.

In the other family that spoke about the child's epilepsy causing conflict in the parent-sibling relationship, this conflict appeared to be more ongoing and did not only occur at times when the child had a seizure. As Samantha, the parent, explained 'he's [Daniel] always saying he [Harry] gets

more attention, always'. She also said that such comments sometimes led to arguments between Daniel and his parents.

Daniel confirmed Samantha's statement and spoke about feeling his parents did not treat him and his brother fairly. This was primarily because Daniel (11) believed Harry's behaviour was a result of his epilepsy, which he thought 'puts loads of stress on the family, and everyone gets mad'. Furthermore, Daniel explained that he did not think his parents responded appropriately to Harry's 'annoying' behaviour, which is evident in the extract below.

I: What if he's annoyed you, or anything like that, do you talk to anyone about that?

Daniel: I tell Mum and Dad, but they don't listen.

I: So what do you tell them?

Daniel: Harry's annoying me. They say 'just ignore him then'. That's all.

Daniel felt he and his brother were treated differently and he did not think this was fair. Moreover, Daniel perceived this to be a consequence of his brother's epilepsy as he felt the condition was leading to Harry receiving preferential treatment.

Not only did siblings' perceptions of the intensified parent-child relationship sometimes lead to conflict or bad feeling between siblings and parents, in some families it was seen to lead to conflict in the sibling relationship, which is the focus of the following subsection.

7.3.3 Conflict in the Sibling Relationship

In two of the families one or more family members spoke about how siblings' perceptions of intensification in the parent-child relationship led to conflict in the sibling relationship. For instance, Daniel (11) made his feelings about his brother clear during his interview, as can be seen in the extract below.

Daniel: He wouldn't take them [his tablets] or he would say he's had them but he actually hasn't.

I: Was that because he didn't want to take them or he thought he had taken them?

Daniel: I don't know. He's a really good liar. I'll give him that.

Daniel appeared to resent his brother a lot, which seemed to stem from his perception of Harry's epilepsy and the way in which it was managed by his parents. This again illustrates that Daniel felt his relationships had been affected due to childhood epilepsy.

Samantha, Daniel and Harry's mum, certainly felt this was the reason her sons did not get on. For instance, she said:

It affects Daniel quite a lot because he gets very jealous of the amount of attention he [Harry] gets and he'll say things like 'oh, he's putting that on'. So they don't get on great because he gets annoyed by him quite a lot.

Daniel was the only child in the study who, like the siblings in Bluebond-Langer's (1991) research, tried to construct their brother or sister as 'normal' in order to be able to demand the same treatment from their parents. For example, Daniel would claim his brother was 'putting it on' and was actually no different to himself. Possible reasons as to why other siblings did not appear to act in the same way will be addressed later on.

Within this family, Harry (8) also felt he and his brother did not get on well; however, he did not attribute this to his condition, as can be seen in the extract below.

Harry: He [Daniel] doesn't think anything about me, he doesn't even care.

I: No? You don't think he cares?

Harry: He's mean to me most.

I: Why do you think he's mean to you?

Harry: Erm, don't know. I can't remember when he started hating me.

Therefore, although Samantha and Daniel felt the sibling relationship had been affected by childhood epilepsy, Harry's comments illustrate that he did not. This was because Harry did not feel conflict in his relationship with his brother was attributable to his condition.

There was one other family where the parent felt her son's epilepsy had had an impact on the sibling relationship. Zara said:

I think they would have always had some sort of competition but I think it is worse. We've had problems where we've had to speak to school because we had problems with Nathan bullying Isaac and we had to get the school to get on top of it. During school time he was getting his friends to pin Isaac down and then he was beating Isaac across the head with sticks and things. Yeah. And that was probably as the epilepsy thing was starting to settle down. And it's probably his frustration at the amount of attention that Isaac gets.

Therefore, similarly to Samantha, Zara felt her sons' relationship had been affected because she thought the rivalry, particularly on Nathan's part, had intensified as a result of Isaac's epilepsy. An additional similarity between Zara's and Samantha's families was that these were the only two families where there were two brothers and the younger of the brothers had epilepsy. Potentially the conflict between these brothers was associated with gender roles within the family as girls were more likely to be involved with their brother or sister's care and, consequently, may have felt more included within the family. Siblings' caring roles will be discussed in more detail in a subsequent section.

Although Zara perceived conflict in her sons' relationship to be the result of childhood epilepsy, Nathan (11) said he did not agree during his interview.

Nathan: Well, he did get a bit more attention in the sort of month it had all been happening, but I wasn't too bothered about it because it was for a good reason.

Therefore, either Zara incorrectly interpreted Nathan's behaviour as a response to Isaac's epilepsy, or Nathan had felt left out during this time but did not want to admit this to the researcher. Based on previous research it is possible that the latter is true; Mayall (1998) has argued that children are taught to manage their emotions and to only express those that are socially acceptable, and Frank (2002) found that siblings may resent additional attention that children with an illness or disability receive, even if they understand why that additional care and attention is necessary.

Nathan, Zoe and Natalie, quoted above, in contrast to Daniel, said they felt it was reasonable and understandable that their brother or sister with epilepsy would receive more attention from their parents as a result of their condition. The extent to which siblings are understanding of their brother or sister receiving more attention may, therefore, be linked to their perception of the condition. Nathan, Zoe and Natalie all perceived their brother or sister to be unwell, whereas Daniel felt his brother was misbehaving and 'lying'. This links to, Bluebond-Langer's (1991) finding that siblings felt less justified in making demands relating to parental treatment and attention during the latter stages of the child's cystic fibrosis. Although siblings understanding why their brother or sister was receiving more attention meant there was less likely to be conflict in family relationships as a result of childhood epilepsy, it did not necessarily mean siblings' family practices had not been affected; for instance, as Zoe explained, she still felt left out.

In other families it was not intensification in the parent-child relationship that caused siblings' frustration, but rather the child's symptoms. For example, when children had absences they often missed what people were saying or repeated themselves, and some siblings found this annoying. For instance, Emma explained:

She [Natasha] gets really agitated when he [Tom] repeats things a lot and she's started to shout and call him names. So she's obviously really frustrated with it.

Similarly, Zoe (16) said when she was woken by Rosie's seizures during the night that she would sometimes feel annoyed with her.

Zoe: Sometimes I did get a bit moody. But like, I never really meant to, it's just like as soon as you wake up it's like 'ugh'.

I: So literally as you woke up?

Zoe: Yeah. It was always as soon as I woke up and then I could hear it and if she was like awake I used to tell her to shut up. [Laughs] I felt really mean but it was just, yeah.

As these extracts demonstrate, it was sometimes the child's symptoms that caused conflict between the siblings, rather than siblings' responses to the intensified parent-child relationship. Indeed, this was the opinion given by one or more family members in five of the 23 families. Consequently, epilepsy could affect family relationships if siblings' perceptions of symptoms caused tension in the sibling relationship.

In this section it has been shown that many family members spoke about how family practices had changed as a result of the child's condition and some felt this had negatively affected the parent-sibling relationship and/or the sibling relationship. Another way in which family practices were altered in these families was through siblings taking on specific caring roles, which are the focus of the following section.

7.4 Siblings' Caring Roles

It has previously been argued that caring is one of the key aspects of the sibling relationship (Edwards *et al.*, 2005; Mauthner, 2005; Sarre, 2010). In almost all the families it seemed that this caring aspect of the sibling relationship came to the fore as a result of childhood epilepsy. Here, 'caring' is defined using the main features of Weisner and Gallimore's definition:

Activities ranging from complete and independent full-time care of a child ... to the performance of specific tasks for another child under the supervision of adults or other children: it includes ... "keeping an eye out" for ... siblings. (1977: 169)

Importantly, Weisner and Gallimore's (1977) definition has been adjusted slightly; the reference to older siblings caring for younger siblings has been removed as it was found that younger siblings also provided care for their older brothers or sisters with epilepsy.

Despite only one sibling in the 23 families being officially recognised as a 'young carer', it was found that siblings in 20 of the 23 families, at times, provided care for their brother or sister who had epilepsy. Indeed, many took on specific caring roles. Building on Clare Williams' (2000) work, it will be argued that siblings acted as 'alert assistants' by informing an adult when their brother or sister was having a seizure. Some siblings also fulfilled a substitute parent role, similar to the 'minimothering' described by Mauthner (2002), where they took on parenting responsibilities when a parent was not present. Additionally, the parenting assistant role will be introduced and discussed, which was fulfilled by siblings when a parent was present and siblings helped that parent to care for their brother or sister. Below, these three caring roles are described.

7.4.1 Alert Assistants

Charmaz (1991) originally used the term 'alert assistant' to describe those who help people with a chronic illness to conceal their condition. Clare Williams (2000) then developed and further defined the concept when she explored the gendered aspect of care giving by mothers of teenage sons with asthma or diabetes. Williams (2000) described mothers as alert assistants when they identified or anticipated their sons' needs and then met those needs. She also argued that this type of care work was often invisible and stated that the alert assistant concept could be developed further in other contexts. Here the concept is expanded by exploring the way in which age was associated with the duties related to this role in the context of childhood epilepsy.

The alert assistant role in this context refers to siblings monitoring their brother or sister for symptoms, recognising their seizures, alerting an appropriate adult and often caring for their brother or sister until an adult could be present. Consequently, here the 'alert' aspect of this role applies in two ways – firstly siblings were alert to their brother or sister's symptoms and, secondly, they would alert an adult that their brother or sister was having a seizure. For instance, below Sarah is explaining how her daughter fulfilled this role.

She [Ellie] was brilliant like because she'd be trotting along behind him [Chris] and just come running up to me and go 'Mummy, Chris's gone again', when he had an absence. And then she'd run back to him and stay with him until I got to him.

Similarly to the mothers described by Williams (2000), and as the above extract demonstrates, siblings' care work went some way to meeting the needs of the child with epilepsy. However, when fulfilling this role, rather than caring for their brother or sister for the duration of the seizure, siblings would alert an adult who would then take over from them.

Siblings did not necessarily take on this role automatically. It was illustrated in Chapter Four that siblings, like parents, did not always immediately recognise their brother or sister's behaviour as a seizure. For example, Steve and Nicola spoke about one incident when Chloe had thought Zak was ignoring her when he was actually having a seizure. However, in this instance Nicola and Steve taught Chloe to recognise Zak's seizures to enable her to fulfil the alert assistant role in the future. Below Chloe (6) is describing her involvement in a particular incident when her brother had a seizure in the garden.

What happened is he just started to just stare. And I knew, I went in [the house] and I said 'Zak's staring'. Because it didn't look like, because about three seconds ago he was playing with us. So I just said 'he's staring'. Because I didn't know if he was actually like having one or not. And Mum and Dad went out and they sorted it out while my friend got all her stuff together because she was going.

Chloe's statement shows that she still experienced some uncertainty regarding whether her brother was having a seizure but it also clearly demonstrates her fulfilment of the alert assistant role. She recognised her brother's symptoms and alerted her parents; for her, these two points are the central aspects of her story before her parents took over the responsibility of caring for her brother. Importantly, this is where Chloe's description of this incident ends as she had carried out her duties.

Children generally fulfilled this role when they were not in the presence of their parents as it was seen to be the parent's responsibility to recognise their child's seizures if they were present. Indeed, some children also took on the alert assistant role at school when teachers did not notice their brother or sister's seizures. This was particularly the case for the twin siblings that took part in this study, who were in the same class at school, which is described by their mother, Catherine, below.

Catherine: Elliot knows Molly and her symptoms so well that he'll often tell the teachers at school 'Molly is having a crinkle [seizure]. Go and help'.

In his individual interview, Elliot (8) also explained that he would inform an adult when he saw his sister have a seizure at school:

Elliot: We get the nurse. And we get one of our really nice teachers, called Mrs. Murfitt, and if it's really bad we get Mrs. Murfitt and Mrs. Murfitt calls my mum.

I: So do you sometimes tell the teachers if you see her having one?

Elliot: Yeah.

Therefore, Elliott regularly took on the alert assistant role when his parents were not present, even though other adults were. Siblings were able to take on this role when other adults were present due to the experiential knowledge they possessed as a result of the number of their brother or sister's seizures they had witnessed.

Some parents spoke about how siblings filling this role meant they could allow the child with epilepsy more freedom from parental supervision than they may have otherwise been afforded. This was because parents trusted siblings to recognise the child's seizures and alert them or an alternative adult. In much the same way that Williams (2000) argued that the work of alert assistants was often invisible to the outside world, siblings fulfilling the monitoring aspect of this role often went unnoticed by those outside the immediate family. However, in contrast to Williams (2000) who found that alert assistants' work was also invisible to the child with the chronic illness, this was not always the case in this study, as sometimes parents informed their child that they needed to stay with their brother or sister in case they had a seizure. Nevertheless, in other instances, siblings unconsciously took on this responsibility despite parents relying upon them. As well as the alert assistant role, some siblings also took on the role of a substitute parent, which is discussed in the following subsection.

7.4.2 Substitute Parents

Similarly to the alert assistant role, the substitute parent role was also fulfilled when parents were not present. However, the main difference between the two roles is that the substitute parent role entailed a sibling taking on the primary caring responsibility for the child with epilepsy when a parent was not present, rather than transferring that responsibility to an adult.

In two families where siblings took on a number of responsibilities related to the role, parents referred to the sibling as a 'mini mum' or taking on a 'mum role'. For instance, Anita explained:

She [Natalie] is like a mini mum. Obviously I've just finished my nurse training and I've had to rely on her a lot really ... because obviously there's been times when if Kevin [Dad] hasn't got in until late or, another thing, you know, I don't like her [Lydia] cooking on her own. She does if I'm here, but Natalie will cook for her and stuff like that. Because pans of hot water if you're making

pasta and stuff [Laughs] if you have an absence isn't great so yeah, you know, Natalie is like a mini mum.

Similarly to the way in which Mauthner (2002) described the care sisters provide as 'minimothering', Anita's use of the term 'mum' suggests that the provision of this type of care is gender specific. However, it was found that when fathers were present in these families, they also provided the same types of care; consequently, siblings taking on these responsibilities are referred to as substitute parents rather than substitute mothers.

Natalie supported Anita's assertion that she provided a substantial amount of care for her sister, Lydia. The photographs Natalie (14) had taken relating to epilepsy were mainly of comments she had written about the responsibilities she took on when caring for her sister. For example, when explaining one of these comments she said:

That's what I have to do every morning. I walk her to and from school. And I cook Lydia's tea if my mum's at work or whatever. And then look after Lydia all the time because of her epilepsy.

Natalie's and Anita's extracts illustrate that she acted as a substitute parent by taking on the caring responsibilities that related to her sister's epilepsy when her parents were not present.

Zoe took on a similar role in her house. However, she was also responsible for measuring Rosie's medication and ensuring her sister took her medication when her mum was not home. Below Zoe (16) is explaining she also took on this responsibility even when adults other than her mum were present.

My Nan, like when she first started giving it [medication] to her [Rosie] and that, like when we stay there she always was like worrying. She's like 'is it right? Is it right?' And telling me, and I'm like 'yeah'.

This quote shows that Zoe took on this role even when other adults, such as her grandmother, were present. Much like the siblings who fulfilled the

alert assistant role when other adults were present, Zoe was able to act as a substitute parent because she had the necessary experiential knowledge.

As well as taking responsibility for medication, walking their brother or sister to and from school and cooking for them, siblings also took on other responsibilities as part of the substitute parent role. Most commonly, all substitute parents would care for their brother or sister whilst they were having a seizure, as the following extract from Nathan's (11) interview demonstrates.

Nathan: Usually I would stay with him because I wouldn't like Isaac to have one on his own, so I would stay with him. But after it me and Isaac would go tell that it's happened ... There's nothing much we can do apart from sit with him and just talk to him.

I: What sort of things might you say to him?

Nathan: Just telling him it's OK, it will be over in a bit. Things like that.

This quote illustrates an important aspect of the substitute parent role that makes it differ from the alert assistant role – siblings would alert an adult during the seizure when fulfilling the alert assistant role, but substitute parents would care for their brother or sister and inform a parent when the seizure had finished (or sometimes the following morning).

Some siblings of children on the ketogenic diet also acted as substitute parents by ensuring the child on the diet did not consume restricted foods. Furthermore, in one family the sibling took on responsibility for preparing her sister's meals when her mother was not present, as Grace (11) explained:

Grace: Well, I would always know things that Faye would like to eat in the diet so I could always prepare it or make it if Mum was away or going out somewhere or busy in the office. Or just wanted a break. [Laughs]

I: So you knew how to make some of the meals?

Grace: I knew how to make most of them and I could, using ...

Ellen: That chart. That exchange ...

Grace: Using, yeah, we had an exchange thing and I loved making

up new menus and dishes for Faye. So I could easily just put something together if we didn't have the right amount of courgette or banana or blueberries.

Here Grace is describing that she could not only follow ketogenic recipes, but she could also create new meals by substituting one food for another whilst still ensuring the meal was of the correct nutritional value. Importantly, Grace also emphasises that she did this when her mum was not available to make her sister's meals. Like many siblings, Grace continued to fulfil this role when other adults, in theory, had responsibility for their brother or sister. For instance, Ellen said 'when Peter and I went away for a week my mother did the diet for a week but Grace actually really did it'. The family went on to explain that the grandmother would have given Faye the same meal every night and that Grace had cooked for her sister so that she could eat something different. This story again illustrates that siblings who took on the substitute parent role often had high levels of experiential knowledge relating to their brother or sister's condition and/or treatment, and were consequently in a position to provide care when other adults were unsure.

It was found that siblings would sometimes care for their brother or sister differently depending on the type of seizure they were having. For example, Elliott (8) would alert his mum if Molly had a tonic clonic seizure (loss of consciousness and contraction of the muscles followed by jerking movements) at home but if she had a 'crinkle' (a type of focal seizure where the child remained conscious) at home he said he would 'just hug her until it ends'. This is in line with existing research on young carers, which suggests that the nature of the person's disability or condition influences the type of care provided (Aldridge and Becker, 1993; Frank, 2002; Dearden and Becker, 2004; Smyth *et al.*, 2011). However, in this study the situation also appeared to be a significant factor determining the type of care provided; for instance, when at school Elliott said he would tell a teacher if Molly had any type of seizure. Therefore, although the alert assistant and substitute parent roles were different, siblings sometimes alternated between the two

depending on the situation or the type of seizure their brother or sister was having.

Furthermore, similarly to the alert assistant role, parents spoke about how siblings acting as substitute parents allowed the child with epilepsy more freedom; this was because parents felt they could increase the space between themselves and their child with epilepsy if a sibling was present because they trusted siblings to care for their brother or sister. The final way in which siblings supported their parents in caring for their brother or sister was by fulfilling the parenting assistant role, which is discussed below.

7.4.3 Parenting Assistants

The role of parenting assistant differed to the alert assistant and substitute parent roles because siblings would fulfil this role when their parents were present. Parenting assistants helped parents to implement care regimes or tried to ensure that their brother or sister was included in family practices despite their condition and/or its treatment. Importantly, when taking on this role siblings aided their parents while their parents took the lead.

In one family using the ketogenic diet siblings acted as parenting assistants by encouraging their sister to comply with her treatment regimen, as Rachel, Daisy's mum, is explaining below.

When we did blood tests as well, she [Daisy] used to hate the blood tests, so Emily and Adam would have their bloods tested as well for her ... And the osteocare, which is the mineral supplement that I've now started to give her, she really doesn't like it but we're getting more and more down her. She didn't want it the other day and I said 'look, Emily and Adam are going to have some'. So I gave them some as well. And she seemed a lot happier that they were having it as well. They are very good, very understanding of her epilepsy.

Rachel's statement suggests that it is not only siblings who can feel they are being treated unfairly as a result of childhood epilepsy; here it was Daisy who seemed to feel more content when her brother and sister were participating in her treatment regimen as they were all being treated equally. Consequently, these siblings fulfilled the parenting assistant role by helping their mother to implement their sister's treatment regime.

Additionally, some siblings also assisted their parents by coming up with ketogenic meals when their parents were struggling. For example, Rachel also said:

Emily [sibling], you know, sometimes when I've been wracking my brains thinking 'oh God, what can I give her [Daisy] next?' And I've said to my husband 'what can I give her?' And he'll come up with some really ridiculous answer and then Emily will say 'well, what about if you put some butter in', because she's seen me preparing things. And she's actually come up with some really good ideas, Emily has.

Similarly, below Jane explains that her daughter had thought of ways to ensure her brother on the diet was included in family practices.

When we had family round we chose to not have a pudding, and that was my daughter's idea. She [Kerry] said 'can't we just have cheese and biscuits, because Toby can have the cheese'.

Parents within these families often commented on how helpful siblings were in aiding them not only in implementing the diet, but also by ensuring the child on the diet was as happy as possible despite the inherent restrictions on their food consumption.

Some siblings also fulfilled the parenting assistant role by waiting outside for ambulances or fetching items for their parents whilst their brother or sister was having a seizure. For instance, Catherine said 'they [Aidan and Elliott] just sort of stand back or if I need help if Leon [partner] isn't here they'll run and get a cushion. You know, they're just there'. Therefore, once siblings had fulfilled the alert assistant role they would

sometimes then take on the parenting assistant role. Alternatively, siblings could be called upon to fill this role when they had not been the person to notice their brother or sister's seizure.

Although siblings' family practices were adjusted when they took on caring roles this adjustment was rarely viewed negatively. Moreover, it was illustrated in the previous section that only three siblings said they sometimes felt left out, or that they had in the past. This is in contrast to Dixon-Woods *et al.* who argued that in families with a child with cancer, 'as neither carers nor patients, well siblings may experience difficulties in finding an alternative role within the family' (2005: 111). One reason for so few siblings expressing jealousy, in comparison to other studies (Bluebond-Langer, 1991; Dixon-Woods *et al.*, 2005), could be because the majority of siblings took on at least some caring responsibility for their brother or sister. Therefore, unlike in Dixon-Woods *et al.*'s (2005) study, these siblings did have a role within the family that related to their brother or sister's condition.

It was shown above that the nature of the child's condition and also the context within which a seizure occurred influenced the caring roles that siblings took on. An additional influence on siblings' caring responsibilities was their socio-demographic characteristics, which is the focus of the next subsection.

7.4.4 Socio-Demographic Characteristics and Siblings' Caring Roles

Although siblings moved between the different caring roles and the majority provided some care for their brother or sister, it seemed that certain socio-demographic characteristics influenced the level of care that siblings took on. Within the literature on young carers there is debate over whether the age of the child providing care influences the level of responsibility taken on, with some arguing it does not (Aldridge and Becker, 1993), and others asserting that it does (Dearden and Becker, 2004; Smyth *et al.*, 2011). The

findings of this study concur with the latter viewpoint; of the siblings as a group it tended to be those who were younger who only took on the alert assistant role, whereas those who were older were more likely to take on the broader substitute parent role.

Additionally, although the alert assistant and parenting assistant roles did not appear to be gendered, as male and female siblings seemed equally as likely to fulfill these roles, with regard to the substitute parent role it seemed that gender did have some influence on the extent of the care work taken on by siblings. There were four female siblings and two male siblings who, at times, took on the substitute parent role; however, as can be seen from the data presented above, the girls took on more caring tasks than the boys. The two male siblings who took on this role would care for their sibling during a seizure but did not take on any further caring responsibilities. Consequently, it appears that, in line with the existing literature (Aldridge and Becker, 1993; Dearden and Becker, 2004; Morrow, 2008), some care work is gendered among children.

An additional influence on the care roles that siblings took on was the make-up of their household. The siblings who lived in single parent families or families where there was often only one parent present as the other parent regularly worked away, were more likely to take on higher levels of caring responsibility. For instance, Natalie and Zoe, who took on the most responsibilities out of all the siblings, both lived in these types of household. This finding therefore supports research conducted with young carers, where it was found that family circumstances were influential on the care work taken on by children (Dearden and Becker, 2004; Aldridge, 2008).

Overall, it appears that when taking all of these socio-demographic characteristics into consideration and when comparing the siblings as a group it was those who were older, female and/or those from families where the child to parent ratio was higher (single parent families or those where one parent worked away a lot) that took on the most caring

responsibilities. Indeed, it was the siblings who had all of these socio-demographic characteristics that took on the most caring responsibilities and those who had none or only one of these characteristics that took on the least caring responsibilities.

7.5 Conclusion

This chapter has addressed the following research questions: How does childhood epilepsy affect family relationships? And, to what extent do siblings contribute to informal care practices associated with their brother or sister's epilepsy? It has been shown that childhood epilepsy can affect different dyadic family relationships in a number of ways. Although previous research has highlighted the fact that chronic conditions can influence families' activity participation (Nocon and Booth, 1990; Kelly, 1992; Hill and Zimmerman, 1995; Prout *et al.*, 1999; Barlow and Ellard, 2006; Timmermans and Freidin, 2007), here it has been shown that other everyday family practices can also be affected, which, consequently, can influence family relationships. Furthermore, it has been argued that siblings significantly contributed to informal care practices within the family, as the large majority of siblings took on caring responsibilities relating to their brother or sister's condition. It has, therefore, been demonstrated that chronic illness can affect not only the person with the condition but also other family members, family practices and family relationships.

The impact that chronic conditions can have on family relationships has seldom been noted in previous research findings (see for instance, Veen *et al.*'s (2013) study of families with a child with coeliac disease and Pitchforth *et al.*'s (2011) work on families with a child with a nut allergy). However, it was found here that some parents felt that the parent-child relationship was intensified due to the increased levels of supervision implemented by parents in response to their perceptions of risk (described in Chapter Five). Of those who felt this was the case, one parent considered this to be problematic when there was tension in the parent-child

relationship, and others thought that this intensification either did, or potentially could, negatively affect their relationships with their other children.

Some siblings also commented on the additional time their parents spent with their brother or sister and described feeling left out as a result, which illustrates that emotions are, in part, a product of the social circumstances in which they are produced (Hochschild, 1998; Williams and Bendelow, 1998; Barbalet, 2002). Furthermore, feeling left out may be a common experience for siblings who have a brother or sister with a chronic condition, as this has been found in relation to other illnesses (Bluebond-Langer, 1991; Dixon-Woods *et al.*, 2005). One child in particular also felt this caused problems in his relationship with his parents. Although not all siblings described feeling left out, in some instances their parents nevertheless used their 'emotional dictionary' (Hochschild, 1998) and thought that brothers or sisters were jealous of the attention the child with epilepsy received. This has also previously been found to be the view of parents in families with children with other chronic conditions (Nocon and Booth, 1990; Barlow and Ellard, 2006) and is, therefore, potentially a common parental experience in families with a child with a chronic illness. Overall, some parents felt childhood epilepsy had negatively affected relationships within their families, as they perceived epilepsy to be the cause of problems in the sibling relationship. Similarly, some siblings felt their relationships had been disrupted because family practices within their family had changed and they no longer felt they were treated equally to their brother or sister. Furthermore, siblings, at times, also felt frustrated by the child's symptoms. This analysis has, therefore, revealed two features of the sibling experience that were sometimes underlying causes of sibling frustration – intensification in the parent-child relationship and the child's symptoms.

This research has also provided a more rounded insight into the sibling experience by looking not only at the impact of epilepsy on sibling

conflict and rivalry, but also the effect of childhood epilepsy on the caring side of the sibling relationship. Many siblings took on the alert assistant, substitute parent and/or parenting assistant roles. The development of the alert assistant role has built on the work of Clare Williams (2000) by exploring the generational aspect of this role in the context of childhood epilepsy. In this study, alert assistants monitored their brother or sister, recognised their seizures, alerted an appropriate adult, and cared for their brother or sister until an adult was present. The substitute parent role, however, primarily involved fully caring for the child during seizures and carrying out other caring responsibilities. This was similar to the 'minimothering' carried out by sisters in Mauthner's (2002) study; however, both brothers and sisters took on this role when doing family in the context of childhood epilepsy. The third caring role siblings took on was that of the parenting assistant. This involved helping parents to care for children during seizures and helping to ensure treatment regimens were adhered to. This role differed from the alert assistant and substitute parent roles as siblings only fulfilled the parenting assistant role when their parents were present, whereas the other two roles were taken on in the absence of parents.

Development of these three distinct caring roles as concepts has begun to address a gap in the literature; previous research on children who provide care has either looked at those who are officially defined as 'young carers' (Aldridge and Becker, 1993; Frank, 2002; Underdown, 2002; Dearden and Becker, 2004; Warren, 2007; Aldridge, 2008; Smyth *et al.*, 2011; Wihstutz, 2011) or those who babysit (Weisner and Gallimore, 1977; Kosonen, 1996; Morrow, 2008). The focus here, however, has been on the experience of siblings who care for a brother or sister with a chronic condition, the vast majority of whom were not recognised as young carers. These three roles demonstrate the extent of the care provided by siblings and the important role siblings played in managing childhood epilepsy on a daily basis.

It has also been argued that certain factors are likely to influence the care work taken on by siblings. As has been found in relation to young carers (Aldridge and Becker, 1993; Frank, 2002; Dearden and Becker, 2004; Smyth *et al.*, 2011), the nature of the condition impacted on the roles siblings took on; fulfilment of the alert assistant role was primarily necessary due to the unpredictable nature of epilepsy. Within the young carers literature, some have argued that the age of the child providing care influences the care work taken on (Dearden and Becker, 2004; Smyth *et al.*, 2011), whereas others have argued that age is not an important variable in determining the level of care provided (Aldridge and Becker, 1993). In this study age was found to be influential; when considering siblings as a group, it was the younger ones who were more likely to act as alert assistants and those who were older were more likely to take on the substitute parent role. Furthermore, family circumstances appeared to influence the care roles taken on; siblings from single parent families or families where parents' working schedules meant they were often away from home were more likely to act as substitute parents and take on more caring responsibilities. This finding again aligns with the literature on young carers (Dearden and Becker, 2004; Aldridge, 2008). Within the existing literature it has also been suggested that girls are more likely to provide care than boys (Aldridge and Becker, 1993; Dearden and Becker, 2004; Morrow, 2008). In this study more girls than boys took on the substitute parent role and the girls who did were also more likely to provide a more varied range of caring tasks. However, in relation to the alert assistant and parenting assistant roles, gender did not appear to be an influential factor. Therefore, within this study the effect of gender on the level of care taken on by siblings was only influential with regard to particular roles and tasks.

Chapter Eight: Conclusion

8.1 Introduction

The focus of this thesis has been the experience and management of childhood epilepsy within the family from the viewpoint of children with epilepsy, their parents and their siblings. The aim has been to build on previous sociological research on adults with epilepsy (Schneider and Conrad, 1983; Conrad, 1985; Scambler and Hopkins, 1986, 1988; Scambler, 1989; Shostak *et al.*, 2011; Shostak and Fox, 2012) by providing an account of experiences of this condition during childhood from the perspective of different family members. In doing so, experiences of symptoms, treatments and management of the condition have been explored alongside the implications of the condition for family practices.

This concluding chapter draws together the findings presented in the preceding empirical chapters; it begins with a summary of the key findings and then addresses how this piece of research has contributed to the wider sociological literature. Next, discussions on the limitations of the study and possibilities for future research are presented. The chapter ends with some concluding remarks.

8.2 Key Findings

The primary aim of this thesis has been to answer the following research questions: How do children and their family members experience living with childhood epilepsy? How do families manage childhood epilepsy? To what extent is concealment used as a management strategy for childhood epilepsy in contemporary society? How do family members view medications for childhood epilepsy? How does implementing the ketogenic diet affect the meanings attached to foods? How does childhood epilepsy affect family relationships? And, to what extent do siblings contribute to informal care practices associated with their brother or sister's epilepsy? Here the key

findings are brought together by grouping those that relate to children with epilepsy, their parents and their siblings. This section is consequently split into three subsections: firstly, an overview of children's experiences of living with epilepsy and the ways in which they adapted to the condition are outlined; secondly, parents' experiences of the condition and its treatment are detailed, as well as the ways in which parents managed their children's epilepsy; thirdly, a summary of siblings' experiences of having a brother or sister with epilepsy is provided alongside a description of the ways in which siblings contributed to informal care practices within the family.

8.2.1 Children's Experiences of Epilepsy

All the children spoke about uncertainty associated with the condition. The children described two symptomatic uncertainties regarding the timing of seizures and whether they had had a seizure, and many were also uncertain about the extent to which epilepsy would feature in their future. In order to determine when they had had a seizure the children became familiar with their post-ictal state (period following a seizure). With regard to the future, many of the children talked about being hopeful that their seizures would be controlled through treatment or that they would grow out of the condition.

The children also perceived there to be risks associated with their condition. They talked about the risk of injuries were they to have a seizure in water, near a road or were they to fall from a height. A minority of the children also talked about the possibility of death as a result of seizures. However, the children were primarily concerned about the risk of being stigmatised by their peers. In order to manage this risk, the children either concealed their condition from others or used selective disclosure where they would only talk to certain individuals about their epilepsy.

The children also attached meanings to their treatments. They all talked about how they saw their daily medications as a way of preventing their seizures. However, it seemed that some of the children had originally

believed medications would cure them and, consequently, this meaning developed over time. Indeed, it was necessary for children to come to see their medications as a form of prevention, as they were inclined to stop taking their AEDs when their seizures were controlled if they did not view their medication in this way. The children also saw their AEDs as an unpleasant necessity; although they recognised the positive implications of their treatment (it prevented some or all of their symptoms) they often found ingesting medications to be unpleasant, particularly liquid medications. A further meaning that the children applied to treatments for childhood epilepsy was that they saw them as a symbol of difference; the children who felt different from their peers because of the condition believed treatments drew attention to their epilepsy and, as a result, did not want to take their medications in the presence of others. However, a minority of the children felt that their ability to take tablets provided them with additional status and consequently saw their AEDs as a status symbol.

There were some similarities between the children's experiences of living with epilepsy and their parents' descriptions; however, there were also a number of differences. The key findings relating to parenting childhood epilepsy are discussed in the following subsection.

8.2.2 Parenting Childhood Epilepsy

Similarly to the children, the parents also described feeling uncertain about when their child's next seizure would occur, whether or not their child had had a seizure and the extent to which epilepsy would feature in the child's future. However, they also spoke about a further symptomatic uncertainty related to the severity of the child's next seizure and they more frequently spoke about the possibility of their child having a shortened lifespan as a result of the condition. Furthermore, parents described feeling uncertain during the onset of the condition and they used their 'social clock' (Bury and Holme, 1991) in order to interpret the child's symptoms. Indeed, many initially thought their child's behaviour was normal for their age. However,

parents then became uncertain about what their child was doing and why, and subsequently decided that their child's behaviour was a cause for medical concern. Following on from this uncertainty, parents explained that misdiagnosis and prolonged diagnostic uncertainty were particularly stressful experiences for them. Diagnosis, however, did not end parents' uncertainties; many parents experienced a 'cycle of uncertainty' because neither childhood nor epilepsy were seen to be stable. As a result, parents could not be sure which changes in their child were part of the normal ageing process and which were linked to the condition. It appeared that the only definitive end to this cycle of uncertainty was for medical professionals to confirm that the child's new behaviour was in some way associated with their epilepsy.

The type of uncertainty experienced by parents had implications for the ways in which they responded to uncertainty. Where possible, parents tried to reduce uncertainty relating to the timing of seizures and whether their child had had, or was about to have, a seizure by looking for patterns in the child's symptoms. In relation to uncertain futures, all parents hoped for a positive future and some described living in the present when the future was seen to be too unpredictable. Furthermore, when parents' uncertainties could not be resolved presently, they spoke about 'waiting' for a time when their questions would be answered.

Parents' uncertainties associated with the timing of seizures meant that all parents perceived their child to be at physical risk as a result of the condition. However, some parents also felt, similarly to their children, that there was a risk of their child being stigmatised or growing up to resent their epilepsy. The focus on physical risks was linked to the view of children as existing in the present and the parenting discourse of protecting children from risks. Parents also made reference to the future adult that the child would grow into and these discussions drew on the parenting discourse of encouraging children to grow into competent adults. Nevertheless, it was

found that parents gave priority to physical risks to the current child when managing risks presented by the condition.

Parents managed physical risks by: manipulating the places children could go to and the activities they could participate in; manipulating space or perceived proximity between themselves and their child; and by informing others about the child's condition to ensure that they would be properly cared for. Parents also tried to manage the non-physical risks they believed to be linked to the condition; they would use selective disclosure to guard against the child being stigmatised. However, unlike the children, parents would never use blanket concealment because physical risks were always given priority. Many parents also constructed epilepsy, seizures or having a chronic condition more generally as something that was normal to encourage children not to feel different as a result of their condition.

For parents, medical treatment also formed a significant part of the way in which the condition was managed within the family and, like the children, parents also attached meanings to these treatments. Similarly to their children, parents saw AEDs as a form of prevention and as an unpleasant necessity. However, although parents talked about the same positive implications of drug therapy, the negatives they spoke about were different; the main negative aspect of medication use that the parents discussed was the side effects that they perceived to be related to drug treatment. The dominant meaning parents attached to emergency medications was that they saw them as a saviour. Parents using the ketogenic diet also saw dietary treatment as a literal lifesaver, but additionally as a saviour in the sense that they felt they had (re)gained aspects of their child's personality. In relation to the ketogenic diet it was also found that some new meanings became attached to the child's food. For instance, food came to be seen as medicine and, as a result, fat was seen as good. Furthermore, other meanings usually associated with food and feeding others remained unchanged and were drawn upon to justify food choices (food as a symbol of inclusion and a symbol of love).

Building on the experiences of parents and children with epilepsy, the third group of family members that were considered throughout this research was siblings. It is siblings' experiences of having a brother or sister with epilepsy and their contributions to informal care within the family that are considered next.

8.2.3 Siblings and Childhood Epilepsy

Due to parents' manipulation of space, described above, siblings, as well as some parents, felt that the parent-child relationship had been intensified. It was found that as a result of this intensification, some siblings felt their place within the family had changed as they no longer felt equal to their brother or sister and some described feeling 'left out'. These feelings sometimes caused conflict in the sibling-parent relationship and at other times resulted in tension in the sibling relationship.

However, despite instances of conflict, it was also found that siblings significantly contributed to the informal care provided within the family. Indeed, siblings took on three caring roles – the alert assistant, substitute parent and the parenting assistant roles. The alert assistant and substitute parent roles were both fulfilled when parents were not present, whereas siblings assisted parents with caring responsibilities in the presence of parents when taking on the parenting assistant role. The alert assistant role involved siblings monitoring their brother or sister, recognising their symptoms and alerting an appropriate adult if their brother or sister had a seizure. In contrast to this, the substitute parent role comprised taking on the primary caring responsibility for their brother or sister, including caring for them during seizures. It was also found that certain socio-demographic characteristics influenced the care work that siblings took on. Indeed, siblings who were female, older and from families where there was a higher child to parent ratio were likely to take on the most caring responsibilities.

The ways in which the findings presented in this section have contributed to the sociological literature will be discussed below.

8.3 Contributions to the Sociological Literature

This study has contributed to medical sociology and the sociology of childhood literature in four main areas: children's experiences of chronic conditions, the experience of epilepsy in contemporary society, the experience of implementing dietary treatments and the role of siblings in informal care work within the family. Each of these four areas will now be considered in turn.

8.3.1 Children's Experiences of Chronic Conditions

There has been little research conducted into children's experiences of chronic conditions when compared to the wealth of literature on adults' experiences. However, more has been written on childhood culture. For instance, James (1993) found that children place a high degree of emphasis on 'sameness' and 'conformity'. This study has contributed to the sociology of childhood and the sociology of health and illness by not only providing an insight into children's experiences of epilepsy, but also by exploring how childhood culture can impact upon children's experiences of chronic conditions. Here it was found that the emphasis children place on conformity often meant that children with epilepsy felt different from their peers and were at risk of being stigmatised. Indeed, the children who felt different because of their condition spoke about how they had been teased by their peers in the past. Potentially this childhood culture of conformity may result in children with a number of conditions besides epilepsy feeling stigmatised by their peers if they are seen to be in some way different. Additionally, the risk of being stigmatised meant that children often opted to conceal their condition, which is in line with previous research on adults with epilepsy (Scambler and Hopkins, 1986, 1988; Scambler, 1989, 2011; Iphofen, 1990) and Goffman's (1963) arguments regarding stigmatised

conditions more generally. However, some also used selective disclosure, similarly to Schneider and Conrad's (1980) concept of the 'revolving door', as a way of avoiding epilepsy becoming an identifier or dominant feature of their identity. This study has consequently shown that childhood culture can impact upon the way in which children experience epilepsy and also that these children were active in managing their conditions.

Furthermore, this perception of difference had implications for children's adherence to their treatment regimens; those who felt stigmatised were often reluctant to take their medications in front of others, indicating that, as Goffman (1963) has argued, medications can be seen as stigma symbols. In contrast to this, it was also found that certain children felt they could gain additional status as a result of their treatment. Indeed, some of the children felt that their ability to take their tablets elevated their status, possibly because tablets are often seen as adult medications (Whyte *et al.*, 2002). Some children, therefore, may see tablets as a means of gaining access to the adult world and a higher status. Furthermore, it has previously been found that children administering their own medication can gain status with their peers as it denotes responsibility (Christensen, 1998); however, in this instance medication being seen as a status symbol was primarily the result of the form of the medication. Additionally, it was principally the form the medication took that resulted in children attaching negative meanings to their treatment regimens. Consequently, it has been shown that the meanings children attach to their medications are often linked to the form the medication takes and the process of ingesting it.

8.3.2 The Experience of Epilepsy in Contemporary Society

Much of the research into the experience of epilepsy was conducted in the 1970s and early 1980s (Schneider and Conrad, 1983; Conrad, 1985; Scambler and Hopkins, 1986, 1988; Scambler, 1989). As a result, the findings of these studies may not be applicable to experiences of the condition in contemporary society because society has evolved over time.

This piece of research, therefore, contributes to the sociology of health and illness literature by providing an insight into the experience of epilepsy in contemporary society. It was mentioned above that the children with epilepsy felt stigmatised as a result of their condition; however, in contrast to previous research (Scambler and Hopkins, 1986, 1988; Jacoby, 1994), this did seem to be a result of enacted stigma. Furthermore, this stigma was not learnt within the family, as had been found previously (Schneider and Conrad, 1980, 1983; Scambler and Hopkins, 1988), but was rather a result of children's interactions with their peers.

Moreover, stigma was not parents' primary concern. Here it was found that parents prioritised physical risks to the current child and, as a result, risks associated with stigma were a secondary consideration for parents in contemporary society. Indeed, it has been argued that we are living in a risk society (Beck, 1992) where risk consciousness pervades (Giddens, 1991), and it was in terms of risk that experiences of parenting a child with epilepsy were framed. In line with Beck (1992) and Beck and Beck-Gernsheim's (2002) argument that society is more individualised and people now feel individually responsible for the choices they make, it was also shown that parents appeared to feel solely responsible for protecting their children and felt somewhat torn between the various parenting options available to them. Related to this finding is a further contribution to the sociology of childhood literature; it was found that there is a link between discourses associated with protecting children from risks (Jackson and Scott, 1999; Jenkins, 2006; Gabb, 2008; Hoffman, 2010; Gómez Espino, 2013) and conceptualisations of the current child, and also between ideas regarding the future adult and discourses related to encouraging children to grow into competent adults (Jackson and Scott, 1999; Mayall, 2002; Backett-Milburn and Harden, 2004; Jenkins, 2006; Gómez Espino, 2013). This link and parents' prioritisation of physical risks to the current child may help to explain parents' decisions regarding how to manage epilepsy, and by implication, a number of other childhood conditions in contemporary society.

8.3.3 *The Experience of Implementing Dietary Treatments*

This is the first piece of sociological research to explore the use of a dietary treatment where the entirety of a diet comprises treatment. This is likely to be why the findings of this study have differed from the previous research on the use of dietary treatments within the family. In previous studies it has been argued that all family members often incorporate the same dietary alterations into their eating practices in order to adapt to dietary treatments (Kelleher, 1988; Maclean, 1991; Gregory, 2005; Pitchforth *et al.*, 2011). However, this was not the case in families using the ketogenic diet because the diet had to be medically monitored. Instead, it was found here that parents drew heavily on the meanings attached to foods and also added new meanings or reversed existing meanings in order to adjust to this dietary treatment.

It was illustrated in Chapter Six that meanings associated with food symbolising inclusion within a particular group, for instance through the consumption of a 'family meal' (James *et al.*, 2009; Stapleton and Keenan, 2009), and food symbolising love (DeVault, 1991; Lupton, 1996; Warin *et al.*, 2008) were consistently drawn upon by parents when explaining why they had chosen to feed their children different foods. However, use of the ketogenic diet also meant that new meanings became attached to foods. Indeed, in contrast to Veen *et al.*'s (2013) research where dietary treatment was demedicalised, here food came to be seen as medicine, which is likely to be linked to the fact that it was the entirety of the child's food consumption that formed their treatment. Moreover, despite the negative meanings attached to fat and fatty foods (Lupton and Chapman, 1995; Lupton, 1996, 2005; Counihan, 1999), fat came to be seen positively in families using the ketogenic diet, which shows that the meanings attached to foods can be altered as a result of successful dietary treatment.

Furthermore, parents overwhelmingly saw the ketogenic diet as a saviour. Some felt the diet had saved their child's life by preventing life

threatening seizures and many also felt that they had (re)gained aspects of their child's personality as a result of treatment. Consequently, dietary treatment does not have to be seen as restrictive; in this instance success on the ketogenic diet was actually seen to have increased children's and their family members' quality of life. This is not to say that there were not restrictions inherent in the diet, but that this was not the predominant way in which the diet was viewed.

8.3.4 The Contribution of Siblings to Informal Care Work within the Family

Despite large amounts of care for chronic conditions being provided within the family, there has been no research detailing the extent to which siblings (who are not officially recognised as young carers) contribute to the informal care provided in families where a child has a chronic condition. Consequently, this is the first piece of research that has begun to detail the different roles and responsibilities that siblings fulfil, in this instance in relation to the management of childhood epilepsy within the family.

In her work on the gendered aspect of care giving by mothers of teenage sons with asthma or diabetes, Clare Williams (2000) developed Charmaz's (1991) concept of the 'alert assistant'. Williams (2000) concluded by arguing that the alert assistant concept could be developed further in other contexts. Here it has been shown that, in relation to childhood epilepsy, siblings can take on this often invisible role by being alert to their brother or sister's symptoms and alerting an appropriate adult if their brother or sister has a seizure. Additionally, as was described above, siblings also took on two further caring roles. The substitute parent role was similar to the 'minimothering' described by Mauthner (2002), whereby siblings took on parenting responsibilities when a parent was not present. However, as both male and female siblings took on this role, and because they were substituting for fathers as well as mothers, this caring role has been described here as a 'substitute parent' rather than 'substitute mother' role.

Despite the use of this gender neutral term, it was found that gender did influence the care provided by siblings. Indeed, similarly to the work on young carers, it was girls who took on the most caring responsibilities (Aldridge and Becker, 1993; Dearden and Becker, 2004; Morrow, 2008) when fulfilling the substitute parent role. However, it seemed that both female and male siblings were equally likely to fulfil the alert assistant and parenting assistant roles, suggesting that gender may not be an important factor in relation to all caring roles that siblings can take on. However, again similarly to previous research on young carers, it was found that age (Dearden and Becker, 2004; Smyth *et al.*, 2011) and family circumstances (Dearden and Becker, 2004; Aldridge, 2008) also influenced the extent of the care work undertaken. Indeed, it was older siblings and those in single parent families or where one parent often worked away from home that were likely to take on more caring responsibilities. Consequently, it is suggested that there are some similarities in terms of the socio-demographic factors that influence the care work provided by children, whether or not they are young carers. However, as gender was only influential in relation to the substitute parent role, it is likely that there may also be some differences between young carers and children who provide care but are not defined as young carers. At this stage it is not possible to say what all these differences might be; indeed, there are limitations to all research and it is the limitations of this study to which I now turn.

8.4 Limitations of the Study

The sample for this study was limited in four respects. Firstly, participants were recruited through charities; consequently, families who had not had contact with these charities would not have been informed about the research. Secondly, parents acted as gatekeepers to their children, which means that there may have been children who would have liked to participate but were not given the opportunity, either because their parents did not want them to take part or because parents themselves did not want to be involved in the research. Thirdly, the majority of the families that took

part in the research could be defined as middle class based on financial information on each household. Fourthly, the sample size was small. Consequently, as is the case with the majority of qualitative research (Bryman, 2008), it is not possible to generalise the findings presented here on statistical grounds. However, as theoretical saturation was reached, it can be argued that the findings can be generalised on theoretical grounds (Mitchell, 1983; Seale, 2004; Bryman, 2008).

An additional limitation of the research is that this was a sensitive topic to discuss with children, particularly as a number of them felt stigmatised as a result of the condition. Consequently, although some of the children did talk about their experiences of the condition, others were not happy to discuss their epilepsy, which means there is a limited amount of detail regarding these children's experiences. Furthermore, the children tended to respond to questions with very short answers, again meaning that it was not possible to present children's experiences in the same depth as their parents' experiences. However, this is likely to be a problem in a lot of research involving children.

Furthermore, although the original aim for this research was to compare the views of children using the ketogenic diet to their parents and siblings, it was not possible to interview children using the diet and only one sibling participated. As a result, this research has only been able to present the views of parents who were implementing this dietary treatment. It was found here, and it has been argued previously (Christensen, 1998), that children's and parents' views are not always the same; consequently, the meanings children attach to the diet may differ to the meanings ascribed by their parents. However, the experience of children using the ketogenic diet could be the focus of another piece of research. Other future research possibilities stemming from the findings of this study are the focus of the following section.

8.5 Future Research Possibilities

Based on the findings presented within this thesis it is suggested that there are a number of avenues that could be explored further. In particular, children's experiences of treatment, the use of dietary treatments within the family, parents' experiences of childhood conditions and the ways in which siblings contribute to informal care practices in the family. Each of these areas will now be discussed in turn.

There is little literature addressing the meanings children attach to treatment. It was shown here that children's and parents' perceptions of medications sometimes varied, and when they attached the same meaning this could be the result of different considerations. For instance, when parents spoke about the negative aspects of medications they focused on side effects, whereas the children talked about the process of ingesting medications. There was also evidence to suggest that the ways in which children view medications for chronic conditions may develop or change over time. Here it seemed that some children's original perception of AEDs was based on their view of more common household medications for acute conditions (such as painkillers and antibiotics). However, there is no research specifically detailing children's views of these common household medications. As a result, the meanings children attach to treatments for chronic and acute conditions is a possible area for further exploration. Indeed, it would be interesting to know whether there are similarities and/or differences in children's views of treatment for these conditions.

Also in relation to the experience of treatment, there are a number of questions that can be raised relating to the use of dietary treatment. This research has shown that, in contrast to previous studies (Kelleher, 1988; Maclean, 1991; Gregory, 2005; Pitchforth *et al.*, 2011), family members do not always assimilate dietary alterations into their own eating practices in order to adapt to treatment. Indeed, parents using the ketogenic diet often created ketogenic alternatives so that the child on the diet could eat similar

foods to their siblings and/or peers. This finding suggests that the nature of the diet may influence the ways in which families incorporate dietary treatment into family life. There may be a variety of ways in which families normalise dietary changes and this is another possible area for further exploration.

Additionally, it has been shown that the norms relating to food and eating practices do not have a set hierarchy. In this instance, norms relating to portion size and the child's enjoyment of food were given priority at different times to justify food choices. It seemed that the reason parents focused on these aspects of feeding children was in part related to the nature of the diet; for instance, ketogenic meals are often relatively small because of the high fat content of the diet. Therefore, the norms individuals draw on are likely to be closely linked to the diet under discussion and this is an area that could be investigated further to see what different considerations people make in relation to other dietary treatments.

In Chapter Four the concept of the 'cycle of uncertainty' was developed to explain parents' ongoing experience of trying to determine which changes in their child were normal for their age and which were related to their epilepsy. It may be that this concept only applies to experiences of parenting a child with epilepsy because the condition was seen to be unstable. However, there could be other changeable childhood conditions for which this concept would be useful in explaining parents' experiences. Alternatively, it may be that any chronic condition adds this complicating factor for parents. It would therefore be interesting to know whether this concept is more broadly applicable.

Furthermore, although the concept of the 'cycle of uncertainty' was useful for explaining the experience of all of the parents who participated, when parents in dual parent households were interviewed jointly disagreements sometimes arose. As both parents were interviewed in only a minority of the families, further research could be conducted on dual

parent households in order to explore the dynamic nature of parenting a child with epilepsy in more detail.

As was noted earlier, siblings have been largely neglected in relation to research on the experience of chronic childhood conditions within the family. It was shown here that siblings took on three different caring roles in order to help care for their brother or sister with epilepsy. It would be interesting to know whether some of these roles are applicable to siblings who have brothers or sisters with other chronic conditions. The alert assistant role was necessary in relation to epilepsy because the condition is so unpredictable; it may therefore be the case that this role is taken on by siblings in families where a child has another unpredictable condition. Alternatively, there may be additional roles that siblings take on that are specific to other chronic conditions.

Furthermore, socio-demographic characteristics were found to be key determinants influencing the care roles and responsibilities taken on by siblings. However, it was found that gender was only influential in relation to one of the three caring roles. A quantitative study exploring the relationship between siblings' socio-demographic background and their caring responsibilities for brothers or sisters with chronic conditions would be a useful way of finding out which characteristics are most influential and whether there is a causal relationship between certain characteristics and the type of care provided.

8.6 Concluding Remarks

The findings presented within this thesis have contributed to the sociology of health and illness and the sociology of childhood by providing a detailed insight into the experience of daily life in families with a child with epilepsy in contemporary society. It has been shown that in order to understand the different dimensions of daily life it was important to take a multiple perspective approach and consider the views of the different family

members (the children with epilepsy, their parents and their siblings). Indeed, siblings have been a neglected group, but it has been demonstrated here that they significantly contribute to informal care practices within the family. Additionally, this is the first piece of research to explore the social aspects of implementing the ketogenic diet and it has been shown that although some meanings attached to food remained unchanged, others were adjusted or replaced by new meanings. Furthermore, it was illustrated that children and their parents have different views regarding the condition and how it should be managed; children prioritised guarding against the risk of stigma, whereas parents primarily focused on protecting children from physical risks. Overall, the research presented in this thesis has shown that family members' experiences of epilepsy are complex and that the condition can impact on family practices in different ways.

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Appendices

Appendix 1

Group Interview Schedule

Explain the purpose of the research and what the findings will be used for.

Go over ethical considerations and get informed consent.

Explain the task and show the participants own weekday and weekend plan.

Weekday

- How are family members woken in the morning?
- What do they do when they get up? Getting ready for school routine?
- Breakfast: Who makes it? What do they eat? Where do they eat? Who do they eat with?
- How do children get to school? What do parents do during the day?
- What do participants have for lunch?
- How do children get home from school? When do parents get home?
- What do children do after school? Any clubs or activities?
- Do siblings spend time together?
- Do parents help children with homework?
- Evening meal: Who makes it? What do they eat? Where do they eat? Who do they eat with?
- What do parents do in the evening?
- What do children do in the evening?
- When do participants go to bed? Is there a routine?

Weekend

- How are family members woken in the morning?
- What do participants do when they get up?
- Breakfast: Who makes it? What do they eat? Where do they eat? Who do they eat with?
- What activities do different family members do during the day? Which (if any) activities do they do together?
- Lunch: Who makes it? What do they eat? Where do they eat? Who do they eat with?
- Evening meal: Who makes it? What do they eat? Where do they eat? Who do they eat with?
- What activities do different family members do in the evening? Which (if any) activities do they do together?
- When do participants go to bed? Is there a routine?

Thank them for their time and participation.

Give children cameras and instruction sheets and explain camera task. Give parent the envelope to return the cameras.

Appendix 2

Parents' Interview Schedule

Go over ethical considerations and confirm the participant is still happy to participate.

Child's epilepsy history

- First seizure
- Diagnosis
- Type of seizures
- Frequency of seizures
- Medication history
- Treatment side effects
- Triggers

Impact of family life

- Parents' time?
- Parents' sleep?
- Family holidays and days out?
- Siblings' reactions to seizures?
- Parents' reactions to seizures?
- Friends', strangers' and wider family members' reactions to seizures?
- Is epilepsy stigmatised?
- Impact they feel the child's epilepsy has had on family life and interactions

Food and Eating

- Who is responsible for food shopping? Food preparation? What are family members' likes and dislikes?
- Is food ever used as a treat for children? Or a punishment?
- Follow up on anything from group interviews?

For those using the ketogenic diet

- How long does meal preparation take?
- Daily food routine?
- What are the child's food preferences?
- How much does the diet cost?
- How much additional effort is it to source ingredients/prepare food?
- How long did the diet take to adapt to?
- Do family members eat at the same time as one another?
- How are special occasions (e.g. Christmas) approached?
- How has the diet impacted on family life and family interactions?
- What were other family members (e.g. siblings) reactions to the diet?

Thank them for their time and participation.

Appendix 3

Camera Instruction Sheet

Families with a Child/Young Person with Epilepsy – Camera Task

How to take the photos:

- Wind the camera on every time you want to take a new photo



- Press the small button and wait for the light to come on if you are inside
- Push the big button down to take the photo



Your first photo: Please either write your name on piece of paper and take a photo of it or ask someone to take a photo of you.

Next: take at least one photo on each of these topics:

1. The people I live with
2. Things I like to do with my family
3. Food and eating in my family
4. What epilepsy means to me

You can take the photos in any order but you can only take 24 photos altogether.

When you take photos of people, check with them first that they are happy for you to do this.

Have fun! 😊

Appendix 4

Children's Interview Schedule

Go over ethical considerations and confirm the participant is still happy to participate.

Who I live with

- Explain their photos: who, where, when?
- Tell me who people are and something about each person (e.g. what do they like? What do they dislike? Any hobbies?)

Things I like to do with my family

- Explain their photos: who, where, when?
- How often do they do these activities?
- What do they like about doing these things with their family members?
- Is there anything they dislike about these activities with their family members?
- Any stories about times doing these activities in the past?
- Favourite family holiday?

Food and eating in my family

- Explain their photos: who, where, when?
- Favourite food?
- Foods they dislike?
- Who makes their food?
- Favourite sweets/chocolate? When do they get them?

My experience of epilepsy

- Explain their photos: who, where, when?
- What happens when they/their sibling has a seizure?
- What happens after they/their sibling has a seizure?
- How they feel when they/their sibling has a seizure?
- Anything they/their sibling cannot do because of epilepsy?
- How they feel about their/their sibling's treatment?
- Any problems taking medication? Taste of medicine or swallowing tablets?
- Have they had any tests because of their epilepsy?
- How do they feel about their doctors visits?
- Do they think they/their sibling is any different because of their epilepsy?
- Do they think other people view them/their sibling different because they have epilepsy?
- Do their parents treat them any differently?
- Do people at school know they/their sibling has epilepsy?
- Do they ever talk to anyone about their/their sibling's epilepsy?

Thank them for their time and participation.

Appendix 5

Information Sheet for Parents of Children Using Medications



Families with a Child/Young Person with Epilepsy Research

My name is Michelle Webster and I am a research student at Royal Holloway, University of London. I am currently carrying out a piece of research funded by the Economic and Social Research Council in conjunction with Epilepsy Action. This piece of research focuses on families with a child with epilepsy aged between 7-14 years old and the impact that the condition can have on family life and family relationships. Epilepsy Action hopes that the findings of this study will help them to support families in similar situations.

Who can take part in this research?

The research focuses on families who have a child with epilepsy aged between 7-14 years old and another child in the same age range, both living in the same household. I would like to speak to one parent/carer, the child with epilepsy and one sibling aged 7-14 years.

What does the research entail?

I will be audio recording each stage of the research so I can listen back to it at a later date.

1 Group Interview

I would like to start by talking to everyone together. I will ask you to jointly make a plan of what everyone does on an average weekday and what everyone does on an average weekend day. I will provide paper and pens and each family member can choose whether they want to write, draw or both. If any family member would rather not write or draw they do not have to and can still join in with the discussion about what to include.

I will first show you plans I have made about what I do on weekdays and at weekends to give everyone a chance to get to know me first.

I can visit you at your home if this is the most convenient location for you and your family. We can arrange a time and day that is suitable for everyone taking part. It is expected that the group interview will last between 45 minutes and an hour.

Individual Interviews with a Parent/Carer

I would then like to return at a later date and individually talk to one nominated parent/carers. The topics I am looking to cover include:

- Food and eating practices in your household
- Everyday interactions between you and your family members
- Everyday interactions between other family members
- The way you feel epilepsy has affected your family life

I anticipate that this interview will last approximately one hour.

Individual Interviews with Children

The children/young people in this research (those with epilepsy and their sibling) will be given a disposable camera and asked to take photos on four topics over the course of approximately one week. The topics they will be asked to take photos on are:

- The people I live with
- Things I like to do with my family
- Food and eating in my family
- What epilepsy means to me

I will collect the cameras or provide you with a stamped addressed envelope to return the cameras. I will develop the photos and then return to talk to the children/young people individually about the photos they have taken. Each child/young person will be given a set of his/her photos to keep. I expect that this interview will last approximately 30-45 minutes with each child/young person.

Who will know what I have said and what my family members have said?

I will be unable to disclose any information that is discussed in the individual interview with other family members. I will also be unable to show you the photos your children have taken. Although I cannot disclose this information, everyone is free to discuss with each other the information they have disclosed or the photos they have taken, with whomever they choose.

In the write up of my research I may use quotes from you or your family members. I will change the names of everyone involved and any other identifying information so that you will be unrecognisable to the reader and can therefore remain anonymous. If any photos are included in my write up I will obscure the faces of any people in the photos so that you, and other family members, will be unrecognisable.

Any personal information I possess about you or your family will be stored securely away from the data so the two cannot be matched up.

I will therefore be the only person to know what you and your family members have said, unless you choose to discuss this information with anyone else. However, if child abuse were to become apparent I would be obliged to pass this information on to the relevant authorities.

Are there any risks involved with taking part?

There are no known risks involved with your own, or your family members', participation in this study.

Anyone taking part can choose not to answer any questions if they would prefer not to.

Anyone is able to withdraw from the research at any time, without having to give a reason.

I have gained a clear Criminal Records Bureau check. I will bring this with me when I come to meet you and your family, or I can send you a scan or photocopy if you would like to see it prior to deciding whether you would like to participate.

Additional Information

I will need you and your family members to sign a consent form to say that you have read and understood the information provided and that you are happy to participate. (Children/young people will have to write their name to say they have read the leaflet provide for them).

Please note that your participation in this research is entirely voluntary and you, or any of your family members, are under no obligation to take part. Also, there is no compensation available for your participation in the research.

If you have any questions please feel free to ask, I have provided my contact details on the following sheet. If you decide you would like to be involved then please contact me and we can arrange a suitable time for the group interview and begin from there. If you decide you would not like to take part please let me know. If I do not hear from you I will contact you once more to find out yours and your family members' decisions.

If you decide to take part your family will be provided with a summary of the research findings when the research is complete.

Thank you for taking an interest in my research and for taking the time to read this information sheet.

Researcher's contact details:

Michelle Webster

Centre for Criminology & Sociology
Sociology
ABF10 Arts Building
Royal Holloway
University of London
Egham
Surrey
TW20 0EX

Michelle.Webster.2011@live.rhul.ac.uk

07976030402

Supervisor's contact details:

Professor Jonathan Gabe

Centre for Criminology &
ABS5 Arts Building
Royal Holloway
University of London
Egham
Surrey
TW20 0EX

J.Gabe@rhul.ac.uk

Appendix 6

Information Sheet for Parents of Children on the Ketogenic Diet



Families with a Child/Young Person with Epilepsy Research

My name is Michelle Webster and I am a research student at Royal Holloway, University of London. I am currently carrying out a piece of research funded by the Economic and Social Research Council in conjunction with Epilepsy Action. This piece of research focuses on families with a child with epilepsy aged between 4-14 years old and the impact that the condition can have on family life and family relationships. Epilepsy Action hopes that the findings of this study will help them to support families in similar situations.

Who can take part in this research?

The research focuses on families who have a child with epilepsy aged between 4-14 years old and another child in the same age range, both living in the same household.

What does the research entail?

I will be audio recording each stage of the research so I can listen back to it at a later date.

Individual Interviews with a Parent/Carer

The topics I am looking to cover include:

- Food and eating practices in your household
- Everyday interactions between you and your family members
- Everyday interactions between other family members
- The way you feel epilepsy has affected you family life

I anticipate that this interview will last between one and two hours.

Who will know what I have said?

In the write up of my research I may use quotes from you. I will change the names of everyone involved and any other identifying information so that you will be unrecognisable to the reader and can therefore remain anonymous.

Any personal information I possess about you or your family will be stored securely away from the data so the two cannot be matched up.

I will therefore be the only person to know what you have said, unless you choose to discuss this information with anyone else.

Are there any risks involved with taking part?

There are no known risks involved with your participation in this study. Anyone taking part can choose not to answer any questions if they would prefer not to. Anyone is able to withdraw from the research at any time, without having to give a reason.

Additional Information

I will need you to sign a consent form to say that you have read and understood the information provided and that you are happy to participate.

Please note that your participation in this research is entirely voluntary and you are under no obligation to take part.

If you have any questions please feel free to ask, I have provided my contact details below. If you decide you would like to be involved then please contact me and we can arrange a suitable time to meet. If you decide you would not like to take part please let me know. If I do not hear from you I will contact you once more to find out your decision.

If you decide to take part you will be provided with a summary of the research findings when the research is complete.

Thank you for taking an interest in my research and for taking the time to read this information sheet.

Researcher's contact details:

Michelle Webster
Centre for Criminology & Sociology
Sociology
ABF10 Arts Building
Royal Holloway
University of London
Egham
Surrey
TW20 0EX

Michelle.Webster.2011@live.rhul.ac.uk
07976030402

Supervisor's contact details:

Professor Jonathan Gabe
Centre for Criminology &
ABS5 Arts Building
Royal Holloway
University of London
Egham
Surrey
TW20 0EX

J.Gabe@rhul.ac.uk

Appendix 7

Children's Information Leaflet

Back Cover

- You don't have to answer any questions you don't want to.
- If you say you want to take part you can change your mind at any time.
- You can tell me if you want me to stop recording what you are saying.
- If I use what you say in my report I won't use your name so no one will know you said it. I also won't tell your family members what you say to me.
- If I use any of your photos in my report no one will know you took them and I will not show the faces of any people in your photos.

If you have any questions you want to ask before you decide if you want to take part you can ask me or ask your parent/carer to ask for you.



Have a think, it's up to you if you want to take part in my research or not. Just tell your parent/carer and they will let me know what you decide.

Front Cover

Families with a Child/Young Person with Epilepsy

Would you like to take part in my research?

Have a look inside and see what you think!



Inside Page 1

My name is Michelle and I work at a university.



I have been asked to talk to children/young people with epilepsy and their family members to find out how epilepsy can influence people's lives. The information will be used to improve services for families with a child with epilepsy.

If you decide you would like to take part in my research this is what will happen:

I'll come to visit you when you, one brother or sister and one parent can talk to me together.



I will give you some paper and pens and ask you to all make a plan of what you do on weekdays and at weekends.

You can draw or write on the plan or you can just talk to your family about what you would like them to put on the plan for you.

Inside Page 2



When I leave I will give you a camera and ask you to take photos on four topics:

1. The people I live with
2. Things I like to do with my family
3. Food and eating in my family
4. What epilepsy means to me

I will collect the camera after about a week and then find out when it would be OK for me to come back and talk to you by yourself.

I'll bring you a set of your photos that you can keep and ask you to tell me about what the pictures show.



When I talk to you by yourself and with your family I would like to record what everyone says so I can listen to it again later.

Appendix 8

Consent Form for Parents of Children on the Ketogenic Diet

Families with a Child/Young Person with Epilepsy – Consent Form

Researcher – Michelle Webster

Please tick:

- I have read the information sheet about this study
- I have had the opportunity to ask questions
- I have received satisfactory answers to any questions
- I understand that I am free to withdraw from the study at any time, without giving a reason
- I agree to participate in this study

Signed.....

Name

Date

NB: This consent form will be stored separately from the responses you provide.

Epilepsy Action would like to place audio clips from parents' individual interviews on their website. You can choose whether or not you would like clips from your interview to be submitted to the charity. If you say 'yes' you will be given the opportunity to hear the selected clips from your interview and decide whether you are happy for each individual clip to be passed on to Epilepsy Action.

Would you like audio clips from your interview to be passed on to Epilepsy Action so the charity can use them on its website?

- Yes
- No

Appendix 9

Consent Form for Parents of Children using Medications

Families with a Child/Young Person with Epilepsy – Consent Form

Researcher – Michelle Webster

Please tick:

- I have read the information sheet about this study
- I have had the opportunity to ask questions
- I have received satisfactory answers to any questions
- I understand that I am free to withdraw from the study at any time, without giving a reason
- I agree to participate in this study
- I agree that my children can participate in this study
- I agree that my children can take photographs in my home, of myself and of my family members

Signed.....

Name

Date

NB: This consent form will be stored separately from the responses you provide.

Epilepsy Action would like to place audio clips from parents' individual interviews on their website. You can choose whether or not you would like clips from your interview to be submitted to the charity. If you say 'yes' you will be given the opportunity to hear the selected clips from your interview and decide whether you are happy for each individual clip to be passed on to Epilepsy Action.

Would you like audio clips from your interview to be passed on to Epilepsy Action so the charity can use them on its website?

- Yes
- No

Appendix 10

Children's Consent Form

Families with a Child/Young Person with Epilepsy – Consent Form

Researcher – Michelle Webster

Please tick:

- I have read the information leaflet about this study
- I have asked all the questions I want to
- I have had all my questions answered
- I know I can choose not to carry on taking part in this research, without having to give a reason
- I agree to take part in this study
- I agree that photographs can be taken of me

Name

Date

NB: This consent form will be stored separately from the responses you provide.

Appendix 11

Epilepsy Action Website Advert for Families using Medications

Michelle Webster is a research student at Royal Holloway, University of London. She is conducting a piece of research that is funded jointly by the Economic and Social Research Council and Epilepsy Action. Her research aims to find out how epilepsy affects family relationships.

The research involves two stages. Firstly, a group interview with one parent/carer, the child with epilepsy and one sibling. And secondly, individual interviews with each of the three family members (living in the same household).

Michelle is looking for families with a child with epilepsy aged between 7-14 years old and a sibling in the same age range to participate in the research. She is interested in speaking to families who use anti-epileptic drugs to treat their child's epilepsy.

If you would like more information about the research please contact Michelle using the following details.

Michelle Webster
Centre for Criminology & Sociology
ABF10 Arts Building
Royal Holloway
University of London
Egham
Surrey
TW20 0EX

Michelle.Webster.2011@live.rhul.ac.uk

07976030402

If you contact Michelle please include information about which area of the country you live in and whether your children are in mainstream education.

Appendix 12

Epilepsy Action Website Advert for Families using the Ketogenic Diet

Michelle Webster is a research student at Royal Holloway, University of London. She is conducting a piece of research that is funded jointly by the Economic and Social Research Council and Epilepsy Action. Her research aims to find out how epilepsy affects family relationships and how the ketogenic diet impacts on family life.

The research involves two stages. Firstly, a group interview with one parent/carer, the child with epilepsy and one sibling. And secondly, individual interviews with each of the three family members (living in the same household).

Michelle is looking for families with a child with epilepsy aged between 7-14 years old and a sibling in the same age range to participate in the research. She is interested in speaking to families who use the ketogenic diet to treat their child's epilepsy.

If you would like more information about the research please contact Michelle using the following details.

Michelle Webster
Centre for Criminology & Sociology
ABF10 Arts Building
Royal Holloway
University of London
Egham
Surrey
TW20 0EX

Michelle.Webster.2011@live.rhul.ac.uk

07976030402

If you contact Michelle please include information about which area of the country you live in and whether your children are in mainstream education.

Appendix 13

Epilepsy Action Website Advert for Parents using the Ketogenic Diet

Michelle Webster is a research student at Royal Holloway, University of London. She is conducting a piece of research that is funded jointly by the Economic and Social Research Council and Epilepsy Action. Her research aims to find out how epilepsy affects family relationships and how the ketogenic diet impacts on family life.

Michelle is looking for parents with a child with epilepsy aged between 4-14 years old who are using the ketogenic diet to treat their child's epilepsy. The research involves taking part in a one off interview.

If you would like more information about the research please contact Michelle using the following details.

Michelle Webster
Centre for Criminology & Sociology
ABF10 Arts Building
Royal Holloway
University of London
Egham
Surrey
TW20 0EX

Michelle.Webster.2011@live.rhul.ac.uk

07976030402

If you contact Michelle please include information about which area of the country you live in.

Appendix 14

Epilepsy Action Magazine Advert for Families using Medications

The logo for Epilepsy Action, featuring the word "epilepsy" in white lowercase letters on a blue rectangular background, followed by the word "action" in white lowercase letters on a pink rectangular background.

Research news

Can you help?

Managing childhood epilepsy within the family

Michelle Webster is a research student at Royal Holloway, University of London. She is carrying out a piece of research that is funded jointly by the Economic and Social Research Council and Epilepsy Action. Her research aims to find out how epilepsy affects family relationships.

There are two stages to the research. Firstly, a group interview with a parent/carer, the child with epilepsy and one brother or sister. Secondly, individual interviews with each of the three family members (living in the same household).

Michelle is looking for families with a child with epilepsy aged between seven and 14 years. The child must have a sibling in the same age range, also willing to take part in the research. She is interested in speaking to families who use epilepsy medicines to treat their child's epilepsy.

If you would like more information about the research, please contact Michelle by emailing Michelle.Webster.2011@live.rhul.ac.uk or calling 07976 030 402. Alternatively, write to Michelle Webster, Centre for Criminology & Sociology, ABF10 Arts Building, Royal Holloway, University of London, Egham, Surrey TW20 0EX.

When you contact Michelle, please include information about which area of the country you live in and whether your children are in mainstream education.

Appendix 15

Epilepsy Action Magazine Advert for Parents using the Ketogenic Diet

Do you have a child using the ketogenic diet?

Michelle Webster is a PhD student at Royal Holloway, University of London. She is researching the healthcare decisions that families make about young children when they have been diagnosed with epilepsy.

Michelle would like to speak to parents in the UK who have a child with epilepsy who is following the ketogenic diet.

The child should be aged between four and 14 years and should have a brother or sister in the same age range. To find out more email *Michelle.Webster.2011@live.rhul.ac.uk* or telephone 07976 030 402.

Appendix 16

Epilepsy Action Support Group Flyer



The management of childhood epilepsy within the family Could you help with this important research?

About the study

The project will focus on the healthcare decisions that families make about young children after they have had a child diagnosed with epilepsy. This research aims to find out how epilepsy affects family relationships.

Who is conducting the research?

The research is being carried out by Michelle Webster, a PhD student at Royal Holloway, University of London. Michelle is funded by the Economic and Social Research Council and Epilepsy Action.

Who can take part?

Michelle is looking for families in the UK with a child with epilepsy aged between seven and 14 years old and a brother or sister in the same age range to take part in the research. She is interested in speaking to families who use epilepsy medicines to treat their child's epilepsy.

Michelle would also like to interview families whose child is following the Ketogenic Diet.

What will participants be asked to do?

There are two stages to the research. Firstly, a group interview with a parent/carer, the child with epilepsy and one sibling. And secondly, individual interviews with each of the three family members (living in the same household).

Who has reviewed this study?

The research has been reviewed and approved by Royal Holloway, University of London.

Interested?

If you would like more information about the research, please contact Michelle using the following details, Michelle.Webster.2011@live.rhul.ac.uk, or telephone 07976 030 402.

Or write to:

Michelle Webster, Centre for Criminology and Sociology, ABF10 Arts Building, Royal Holloway, University of London, Egham, Surrey TW20 0EX

When you contact Michelle, please include information about which area of the country you live in and whether your children are in mainstream education.

Appendix 17

Epilepsy Action Facebook and Twitter Adverts for Families using Medications

Do you have a child with epilepsy?

If you have two children aged 7-14, one of which who has epilepsy and is currently taking medication for their epilepsy, then would you be interested in taking part in a research project? More information about the research can be found using the link below.

<http://www.epilepsy.org.uk/research/take-part/projects-you-can-take-part-in/management-childhood-epilepsy-within-family>

If you've got more than one child, but only one of them has epilepsy, what has it been like for the other child? Have they found it difficult to cope with the attention that child with epilepsy gets? Or have they been a caring sibling, helping their brother or sister with epilepsy when they can? Leave us a comment below with your experiences.

Researchers are wanting to talk families in the UK who have both: a child with epilepsy (taking epilepsy meds) aged between seven and 14 years old AND a brother or sister in the same age range.

If you can help, find out more at: <http://www.epilepsy.org.uk/node/62213>

Appendix 18

Epilepsy Action Facebook and Twitter Advert for Parents using the Ketogenic Diet

Do you have two children aged 4-14, one of which who has epilepsy and is currently on the ketogenic diet? If you do and you would be willing to share your experience of using the ketogenic diet, there is a research project currently recruiting. More information about this project can be found using the following link.

<http://www.epilepsy.org.uk/research/take-part/projects-you-can-take-part-in/ketogenic-diet>

Appendix 19

Epilepsy Research UK Online Newsletter Advert

A call for research participants

A research project funded by the Economic and Social Research Council and Epilepsy Action wishes to recruit children between the ages of 7 and 14 years, and their families, to find out about their experiences of epilepsy. The aim of this is to improve information services. For more details please contact Michelle Webster, at Royal Holloway University London, at michelle.webster.2011@live.rhul.ac.uk, or on 07976 030 402.

Appendix 20

Epilepsy Parents and ESUK Facebook Advert

Hello everyone

I'm carrying out some research in conjunction with Epilepsy Action focusing on families with children with epilepsy.

I'm looking for families who have a child with epilepsy aged 7-14 years who is being treated with medications and who has a brother or sister in the same age range.

If you and your children would be interested in taking part in my research more information can be found here:

<http://www.epilepsy.org.uk/research/take-part/projects-you-can-take-part-in/management-childhood-epilepsy-within-family>

Thank you for taking the time to read my message.

Michelle

Appendix 21

The Daisy Garland Website and Newsletter Advert



Ketogenic Volunteers Wanted

Michelle Webster is completing a PhD in conjunction with Epilepsy Action, focusing on families of children with epilepsy.

She is currently looking for parents who have two children aged 4-14 years (with one child currently on, or having been on, the ketogenic diet). Michelle would like to talk to you about your experience of day-to-day life using the ketogenic diet.

For further information please email Michelle at: michelle.webster.2011@live.rhul.ac.uk or telephone her on 07976 030402

Appendix 22

Matthew's Friends Forum Adverts

Hello everyone

I'm doing a PhD focusing on families with children with epilepsy and I'm looking for a few parents who could spare an hour or two of their time to share their experience of day-to-day life using the ketogenic diet.

I'm particularly looking for parents who have two children aged 7-14 years (with one of the children currently on the ketogenic diet).

If anyone is interested or would like some more information please get in contact using the details below.

Thank you for taking the time to read my message.

Michelle

Michelle.Webster.2011@live.rhul.ac.uk
07976030402

Hello everyone

I'm looking for just a couple more parents to share their stories about daily life on the ketogenic diet. If anyone would be happy to talk to me about their experience then please get in contact with me. My email address is:
Michelle.Webster.2011@live.rhul.ac.uk

Thank you again to everyone who has given up their time to speak to me already; it's greatly appreciated.

Michelle

Appendix 23

Epilepsy Society Forum Advert

Hello Everyone

My name is Michelle Webster and I'm conducting some research focusing on families with children with epilepsy.

I'm looking for families with two children aged 7-14, with one of those children being treated for epilepsy with either medications or the ketogenic diet.

I'm interested to hear about how epilepsy impacts on daily life and how family members manage the condition on a daily basis.

The research involves a group interview with a parent, the child with epilepsy and one sibling and individual interviews with each of these family members.

I have information leaflets for parents and children that I can post to you if you would like to find out more. If you are interested in receiving these leaflets then please email me at Michelle.Webster.2011@live.rhul.ac.uk or phone me on 07976030402.

Thank you very much for taking the time to read my post.

Michelle

Appendix 24

Demographics Questionnaire

(Please tick those that apply to you)

Sex:

Female

Male

Ethnicity:

White

English/Welsh/Scottish/Northern Irish/British

Irish

Gypsy or Irish Traveller

White other

Mixed/multiple ethnic groups

White and Black Caribbean

White and Black African

White and Asian

Mixed/multiple other

Asian/Asian British

Indian

Pakistani

Bangladeshi

Chinese

Asian other

Black/African/Caribbean/Black British

African

Caribbean

Black other

Other (please state)

Age:

30 or under

31-45

46 or over

How many people live in your house?

- 3
- 4
- 5
- 6+

Annual Household Income (before tax):

- Less than £16,000
- £16,001 - £26,000
- £26,001 - £36,000
- £36,001 - £50,000
- £50,001+
- Would rather not state

Are you: (please tick all that apply)

- Working as an employee full-time
- Working as an employee part-time
- Self-employed or freelance
- On a government sponsored training scheme
- Away from work ill, on maternity leave or temporarily laid off
- Long term sick or disabled
- A student
- Looking after home or family
- A carer
- Retired

If you are in paid employment:

What is your job title?

How many hours a week do you usually work?

- 15 or less
- 16-30
- 31-48
- 49 or more

If you have a partner who lives in the same household, are they: (please tick all that apply)

- Working as an employee full-time
- Working as an employee part-time
- Self-employed or freelance
- On a government sponsored training scheme
- Away from work ill, on maternity leave or temporarily laid off
- Long term sick or disabled
- A student
- Looking after home or family
- A carer
- Retired

If your partner is in paid employment:

What is their job title?

How many hours a week do they usually work?

- 15 or less
- 16-30
- 31-48
- 49 or more

Appendix 25

List of Codes

- Adults with epilepsy
- Advice from others
- Appearance as a sign of health
- Back to the 'normal flow of things'
- Being a 'good parent' – Moral justifications
- Being fair
- Being lucky
- Care work
 - Alert assistant
 - Parenting assistant
 - Substitute parent
 - Young carers
- Change in the child
- Child getting older – Independence
- Child's age
- Child's choice – 'Ownership'
- Child's personality
- Comparing to children and childhood
- Daily life
 - Additional attention
 - Additional considerations – Planning
 - Adjusting
 - Alteration to sleeping arrangements
 - 'Always on my mind'
 - Arguments – Tension
 - Balancing responsibilities
 - Benefits
 - Changes
 - Counselling
 - Days out- Holidays
 - Disruptions
 - Extended family
 - Family quality time
 - Financial implications
 - Hard work
 - Impact on child
 - Impact on sibling
 - Increasing proximity
 - 'It's the epilepsy that's the problem more than his diet'
 - Mobile phone
 - No difference
 - Normal appearance
 - Others taking on responsibility
 - Over-protective
 - Parental relationship

- Parents' social life
- Personal care
- Restrictions
- School
- Sibling rivalry
- Sleep disturbance
- Social support
- Special occasions
- Supervision
- Tired
- Work
- Death
- Detachment
- Distraction
- Emotions
 - Acceptance
 - Angry - annoyed
 - Anxious
 - Attention seeking
 - Being understanding – Empathy
 - Bored
 - Calm
 - Caring
 - Comfort
 - Confusing
 - Coping
 - Distrust
 - Embarrassment
 - Emotional
 - Excitement – ‘cool’
 - Exhausted
 - Feeling alone
 - Feeling left out
 - Feeling sorry
 - Feeling special – Proud
 - Frightened
 - Frustration
 - Grateful
 - Guilty
 - Happy
 - Hope
 - ‘I hate epilepsy’
 - Jealousy
 - Joking
 - Maturity
 - Obsessive
 - Offloading
 - Others in a similar situation – Identifying
 - Panic

- Positive thinking
- Possessive
- Provoking reactions
- Reassurance
- Relax – release
- Relief - confirmation
- Responsibility
- Shocked
- Stressed
- Stropy
- Trust
- Trying to control emotions
- Unaware
- Uncomfortable
- Upsetting - Distressing
- Worry - Concern
- Epilepsy
 - Anti-suffocation pillows
 - Bed alarm – Baby monitor
 - Cause
 - Changing or new symptoms
 - Charities
 - ‘Clear’ – ‘Seizure free’
 - Conscious
 - Diagnosis
 - Drug resistant
 - Effect of the condition
 - Hospital (emergency)
 - Hospital (routine) or GP
 - I.D.
 - Injuries
 - Knowledge
 - Medical Professionals
 - Misdiagnosis or medical uncertainty
 - ‘Not controlled’
 - Onset
 - Permanent Change
 - Post-ictal
 - Prior knowledge
 - Routine
 - Second Opinion
 - Seizure description
 - Seizure occurrence
 - Seizure severity
 - Seizure type
 - Signs
 - Status
 - SUDEP
 - Syndromes

- Tests
- Timing of onset
- Timing of seizures
- Treatment without diagnosis
- Triggers
- Unconscious
- Unpredictable
- Food
 - 'All are eating different foods'
 - Breakfast
 - Children going off food – Going through phases
 - Choosing what to buy
 - Cleaning up
 - Cooking – Going through phases
 - Cost and offers
 - Drink
 - Eating together
 - Evening meal
 - Fast food – Take aways
 - Fat
 - Favourite foods
 - Healthy option – Dieting
 - Hospital food
 - Incentives – Punishment
 - Intolerance
 - Lunch
 - Packaging
 - 'Picky'
 - Planning
 - Preparation
 - Questioning child's diet
 - Quick – Convenience
 - Routine
 - School lunch
 - Shopping
 - Similar meals
 - Snacks
 - Storage
 - Sweets and chocolate
 - Taste preferences
 - Thinking about implications of diet change
 - Time Constraints
 - Who chooses what they eat
- Getting sibling into trouble – power
- 'I don't believe it's happened again'
- Illness
- Importance of time in life
- Independence
- Infancy comparison

- Informing others
- 'It was a real life change'
- Lack of support and information
- 'Live every day like it's your last'
- Looking for patterns
- Looking to the future
- Main carer
- Making excuses
- Making it up
- Making sense – own interpretation
- Moral evaluation of the child
- 'Mum and dad sorted it'
- 'Mum tells them'
- Needing a break
- New normal – Normalising
- Non-keto knowledge of ketogenic diet
- Not being able to describe
- Not main identity
- Not talking about it
- Not trusting others
- Others reactions
 - Asking questions
 - Child's reactions/thoughts
 - Dismissive
 - Doubt
 - Epilepsy misunderstood/misconceptions
 - Friends
 - General public
 - Grandparents and wider family
 - In the media
 - Incorporating into sense of self
 - Justifying reactions
 - Managing others' reactions
 - Medical professionals' attitudes towards the ketogenic diet
 - Name calling
 - Normal
 - Not understanding
 - Open
 - Other children's reactions
 - Other parents
 - Parents' reactions
 - Partner
 - Sceptical
 - Seeing a difference
 - Seizures misunderstood
 - Siblings' reactions
 - Staring
 - Wanting to do something because you can't
- Out of parental control

- Pain
- Panic attacks
- 'Parental instinct'
- Perceptions of childhood
 - Current child
 - Future adult
- Persistence
- Protecting the child
- Raising awareness
- 'Raring to go'
- Recognising seizures
- Recording seizures and history
- Relationship intensification
- Researching
- Risk
- Seizures on TV
- Sibling Rivalry
- Situational variable
- Stigmatised
 - Being different
 - Concealment
 - Passing
 - Treated differently
- Talking to others
- Talking to parents
- Talking to the child
- Talking to the sibling
- Terminology
 - 'Bad one' Vs 'good one'
 - 'Bad things'
 - Big Vs small
 - 'Dropping'
 - 'Episode'
 - 'Fit'
 - 'Full' – 'Full on'
 - 'Gone again'
 - 'Main event'
 - Naming seizures
 - Naming tests
 - 'Out of control'
 - 'Possessed'
 - 'Seizure'
 - 'The big one'
 - 'We'
- Though seizures had stopped
- Timing consuming
- Treatment
 - 'But at what cost' – Balancing side effects and seizure control
 - Changes

- Child stopping treatment
- Cost
- Daily medication
- Effectiveness
- Emergency medication
- Forgetting medication
- Habitual
- Ketogenic diet
 - 4th Meal
 - 'A constant'
 - Adjustment period
 - Alternatives – Making things the 'same'
 - Appearance of food
 - Batch cooking
 - Brands
 - Changing others' food
 - Child's choice
 - Classical
 - Comparing to other diets
 - Compromise
 - Confidence – Belief in food
 - Deciding which diet
 - Different rules for different people
 - Difficulties
 - 'Doctor says no' – Food not for sharing
 - Eating out
 - Effectiveness
 - EKM
 - Encouraging children to eat or drink
 - Enjoying food
 - Equating meals
 - 'Exchanges'
 - Explaining the diet
 - Fat
 - Feeling of taking things away
 - 'Food as medicine'
 - Food necessities – 'No plan B'
 - Food they can't have
 - 'Free foods'
 - Gastrostomy
 - Health considerations
 - How restrictive is the diet
 - Initiating the diet
 - Ketocal
 - Ketones
 - Learnt what they can and can't have
 - MCT oil and liquigen
 - MCT diet
 - Meal refusal

- Meal replacement
 - Measuring
 - Modified Atkins
 - 'Natural'
 - Not hungry
 - Parent's choice
 - 'Points'
 - Portion size
 - Positive impact
 - Prescription
 - Removing temptation
 - Rules around food
 - Same meals everyday
 - Sugar
 - Sun cream and skin products
 - Supplements
 - Table manners
 - Taste
 - Texture
 - The Food Hospital – TV
 - Time on diet
 - Timing of meals
 - Toothpaste
 - Training
 - Treats
 - Meaning of medication
 - 'Life saver'
 - Prevention
 - Status symbol
 - Stigma symbol
 - Unpleasant necessity
 - Medication reminders
 - Naming treatments
 - Preferences
 - Problems
 - Quantity
 - Sedated
 - Side effects
 - Solutions
 - Surgery
 - Taste
 - Toxic
 - Training
 - Treatment history
 - Trailing
 - Weaning
 - Whose choice
 - Whose responsibility
- Understanding severity

- Being medication
- Comparing between seizures
- Deterioration
- Duration of seizure
- Information after the event
- Level of seizure control
- Making comparisons to others
- Medical staffs' reactions
- Quantity or strength of medication
- Reflecting on past
- Resuscitation training
- Staying in hospital
- 'Waiting game'
- Wanting to meet others in a similar situation
- 'We would do anything'
- Weight

Appendix 26

Webster, M. & Gabe, J. (2016) 'Diet and identity: Being a 'good parent' in the face of contradictions presented by the ketogenic diet', *Sociology of Health and Illness*, 38(3).

Abstract

The ketogenic diet is a high-fat diet used to treat drug-resistant childhood epilepsy. Given that negative meanings tend to be attached to fatty foods and children's food consumption is seen to be the responsibility of parents, the ketogenic diet may be problematic for parenting identity. This paper draws upon in-depth semi-structured interviews with 12 parents from 10 families that have a child whose epilepsy is being treated with the ketogenic diet. The main focus of the paper is the meanings these parents attached to foods and how they were drawn upon or altered to overcome some of the contradictions presented by the diet. It will be argued that the diet was medicalised and parents came to view 'food as medicine'. When viewing food in this way, negative associations with fat were reversed. Furthermore, parents also used food as a symbol of inclusion and prioritised portion size or the child's enjoyment of food in order to use food as a symbol of love. In turn this enabled parents to feel they were being 'good parents'. Overall it seems that diet can be medicalised, and the identity of the good parent maintained, if dietary treatment is successful.

Introduction

The ketogenic diet is a high fat, low carbohydrate diet used to treat drug-resistant childhood epilepsy. It was originally introduced as a treatment for epilepsy in 1921, but use declined with the introduction of the medication diphenylhydantoin in 1938 (Wheless 2008). However, over the past 15-20 years there has been a resurgence of interest in the diet, and its popularity has increased in the United States and the UK (Wheless 2008). Between 2000 and 2007 the number of children being treated with the ketogenic diet in the UK increased by 50%, bringing the total in 2007 to 152 (Lord and Magrath 2010). And recently a leading dietician has claimed that the number of children receiving dietary treatment for epilepsy in March 2014 was 536 according to evidence from the caseload database for UK centres (personal communication). This figure suggests that the number of children on the diet has continued to increase since 2007.

Although the exact mechanisms of the diet are still unknown (Neal et al. 2008), it causes the body to go into ketosis¹ and controls seizures by mimicking the metabolic effects of starvation (Cross 2012). The first

randomised controlled trial, conducted by Neal et al. (2008), demonstrated the diet's efficacy, as it was found that after three months 38% of children on the diet had experienced a 50% reduction in seizures compared to only 6% of the control group who continued to be treated with medications alone.

This paper draws on the experiences of families using three different forms of dietary treatment: the classical ketogenic diet, the Medium-Chain Triglyceride (MCT) diet and the Modified Atkins Diet (MAD). Although the MAD is not medically defined as a 'ketogenic diet', for the purposes of this paper it will be referred to as such due to its high fat content. Furthermore, the parents employing this diet considered it to be a form of ketogenic treatment, as they reported that their child was in a state of ketosis when using the diet. The ratio of fat to protein and carbohydrate on the diet varies between 2:1 and 4:1, meaning that up to 80% of calories are received in the form of fat (Cross 2012). The MAD and classical diets rely on large amounts of butter and cream for their high fat content (Ferrie et al. 2012) while the MCT diet uses MCT oil. Other than the type of fat that each diet uses, the main difference between the diets is that protein is not limited on the MAD. As the findings discussed in this paper relate to all three diets, with no major discrepancies found between them, they will be referred to collectively from now on.

Due to the nature of the ketogenic diet, foods are selected primarily for their nutritional content. Although individuals not on a specific diet may give consideration to nutritional content when making food choices, this is not the principal way in which foods are usually selected (Beardsworth and Keil 1997); rather, food choice is largely a result of the meanings attached to foods and the social context in which they are eaten (DeVault 1991; Delormier et al. 2009; Wills et al. 2011). Indeed, there are norms related to when, where and with whom we eat (DeVault 1991; Counihan 1999; James et al. 2009). As will be outlined below, the ketogenic diet contradicts a number of these norms.

While the number of children being treated with the diet has continued to rise, little is known about parents' experiences of

implementing it. The purpose of this paper is therefore to address how parents managed their identities despite the contradictions raised by the diet.

Food, Identity and Parenting

The meanings associated with different foodstuffs influence food consumption. People often use ideas of 'good' and 'bad' foods to distinguish between those that are perceived to be beneficial to one's health and those that are seen to be detrimental (Counihan 1999; Lupton 2005). Foods that are high in sugar, and particularly those with a high fat content, are viewed as 'bad' foods because they have been linked to the development of a number of chronic health conditions (Lupton and Chapman 1995; Lupton 1996, 2005; Counihan 1999). Health campaigns stretching back to the 1970s have recommended that people should reduce their fat intake (Beardsworth and Keil 1997) and these campaigns have become even more prevalent in recent years (Blank et al. 2009). The high fat content of the ketogenic diet therefore contradicts assumptions about the type of foods that should be eaten.

The meanings attached to foods not only influence food choice but also identity construction. People have been found to make judgements about themselves, and even more about others, based on the types of food they eat; those who consume 'bad' foods with a high fat content are sometimes seen to be 'bad' people who lack self-control (Lupton 1996, 2005; Saguy 2013). Similarly, judgements are often made about parents based on the types of food they feed their children (Dixon and Banwell 2004; Saguy 2013). Indeed, parents often comment that they feel responsible for the provision of healthy meals (Cook 2009a, 2009b; Stapleton and Keenan 2009). Based on this literature, there is potential for parents to feel guilty if they believe they are not feeding their children a diet that is currently deemed to be healthy.

Despite parents feeling responsible for providing children with healthy food, over the past two decades it has been claimed that children's influence over their food consumption has generally increased (Dixon and

Banwell 2004). This has been accompanied by a shift in parenting philosophy, whereby parents now feel that children should be able to express their own opinions and food should not be forced upon them (Dixon and Banwell 2004; Coveney 2006). It appears that this philosophy is particularly prevalent among working class families, where it has been found that children's food choices are readily accepted (Backett-Milburn et al. 2006) and the development of autonomy is encouraged (Wills et al. 2011). The findings of these studies illustrate that the meanings attached to food and eating vary among different classes due to the habitus – acquired dispositions and tastes – of each group (Bourdieu 1984; Wills et al. 2011). It may be the case that the ketogenic diet limits parents' ability to satisfy their child's food requests because of the nature of the diet. Furthermore, due to fat having a high calorific content, portion sizes of ketogenic meals are often smaller than people are used to, meaning that parents may feel they are not providing their child with enough food. Therefore, it is possible that the nature of the diet may cause parents, particularly working class parents, to feel conflicted between implementing the diet and fulfilling their child's food desires.

Food not only has cultural significance for people on an individual level, but also for the family as a whole; this is because love and care are displayed through feeding others and sharing food (DeVault 1991; Lupton 1996; Warin et al. 2008). Although it is acknowledged that family meals can be a site of conflict (Wilk 2010), this cultural ideal is still aspired to in many families, as parents see it as a social event that brings family members together (James et al. 2009; Stapleton and Keenan 2009). While there is no clear, agreed upon definition of what a 'family meal' is, a common feature is all family members eating together and, traditionally, everyone present would eat the same meal (Blake et al. 2009; Gallegos et al. 2011). There is scope for the ketogenic diet to contradict this traditional notion of a family meal because family members are likely to be eating different foods; however, as individuals' interpretations of the family meal vary, whether parents feel the diet does in fact contradict this norm is unknown.

Previous discussions on parenting a child with epilepsy are dated and draw on adults' recollections of their childhoods with the condition, rather than parents' views (Schneider and Conrad 1983; Scambler and Hopkins 1988). However, research focusing on families' responses to the use of diet by a family member for other medical reasons indicates that these other family members often assimilate dietary changes by adjusting their own food consumption, either for practical reasons or to normalise dietary alterations (Gregory 2005; Pitchforth et al. 2011). This response has been found in families where one family member had diabetes (Kelleher 1988; Maclean 1991), a nut allergy (Pitchforth et al. 2011), coeliac disease or coronary heart disease (Gregory 2005). An alternative response, found in families where a child had coeliac disease, was to demedicalise the diet by treating food consumption as 'a matter of choice rather than prescription' (Veen et al. 2013: 592).

To date, the ketogenic diet has only been studied by biological scientists. Consequently, despite the rise in the number of children being treated with the diet, little is known about how parents manage their identities in relation to the contradictions the diet presents. Furthermore, the restrictive nature of the diet means that it differs somewhat from diets that have previously been studied. As a result, there is scope to add to the current literature on the use of dietary treatments within the family. The purpose of this paper is, therefore, to broaden understanding and provide an insight into how parents manage their identities despite the contradictions raised by the diet.

Methodology

A qualitative approach was employed to explore, in detail, parents' experiences of using the diet to treat their children's epilepsy. During 2013 the research was advertised through three UK based charities: *Epilepsy Action*, which supports individuals with epilepsy and their families, and two charities that support families using the ketogenic diet - *The Daisy Garland* and *Matthew's Friends*. The charities placed adverts provided by the first

author on their websites, online forums, social media pages, and in their newsletters.

Parents from 15 families came forward as a result of the adverts and in-depth semi-structured interviews were carried out with 12 parents from 10 of those families. One parent decided not to participate because she had just begun implementing the diet and felt she could not fit in an interview. It is unknown why parents from the other 4 families chose not to partake. Although the sample was small, additional participants were not recruited as theoretical saturation had been reached. Roughly equal numbers of parents were recruited per charity and they had varying levels of involvement with the charities and other parents using the diet. Consequently, it is unlikely that the meanings parents attached to foods were learnt entirely as a result of such interactions.

All families were two-parent families and had between 2 and 4 children. The children on the diet consisted of 4 girls and 6 boys aged between 3 and 10 years. Seven of the children were on the classical version of the diet, 2 were on the MCT diet and 1 was on the MAD. Overall, the data presented below comprise the views of 10 mothers and 2 fathers (where both parents from 1 family participated they were interviewed together; consequently, 2 were joint interviews and 8 were individual interviews). The great majority of participants were White British or White European, with one parent being Asian (foreign-born). Although the families were from a range of socioeconomic groups, the majority were in the top quartile of earners.

Six interviews were conducted face-to-face, 2 were phone interviews, 1 was conducted via Skype and 1 was an email interview. It was not possible to conduct all of the interviews face-to-face due to the location of some of the participants; although UK based charities advertised the research, 2 parents from outside the UK who used one of the charity's online forums asked to participate. Those who were interviewed face-to-face were all from mainland UK, and those who were interviewed using other methods were from non-mainland UK, Eastern Europe and Western Europe (all the interviews were conducted in English). Additionally, the majority of

interviews were conducted with participants in their own homes, with the exception of one, which was carried out in a café at the participant's request.

One limitation of the phone and Skype (without video) interviews was that the researcher was unable to use non-verbal cues and, therefore, at times it was difficult to know whether the participant had finished speaking or whether they were pausing to think. However, when comparing the data, no disparity existed in terms of richness between the interviews conducted in person and those conducted using alternative means. It is acknowledged that all statements participants made were a product of the social space in which they were created (Power 2004). However, it was still felt that in-depth interviews were the most appropriate research technique as they allowed for an in-depth exploration of an under researched area. Furthermore, the presence of both parents in 2 of the interviews undoubtedly shaped the data as there were sometimes disagreements, but this did provide an insight into the perspectives of both parents.

The interviews lasted between one and two hours and focused on the child's daily food consumption and parents' daily routine in relation to implementing the diet. Parents often gave very rich answers and used stories to illustrate their points. Consequently, parents also brought up: their child's food preferences, preparation time, cost, managing the diet on special occasions, difficulties associated with implementing the diet, how they fitted the diet into their daily lives and others' reactions to the diet. If the participants themselves did not raise these topics they were probed about them.

All interviews were audio-recorded and transcribed *verbatim*, with the exception of the email interview. The data were then coded using Nvivo and analysed using a constructivist grounded theory approach (Charmaz 2006). In contrast to Glaser and Strauss' (1999) grounded theory, a literature review was conducted prior to carrying out the interviews in order to gain an understanding of previous research on similar topics. But, in accordance with Glaser and Strauss (1999), themes were developed using the constant comparative method throughout the data collection phase, emerging themes were drawn upon in later interviews to fill gaps in the

analysis, and participants were recruited until categories became saturated. Importantly, a constructivist grounded theory approach was adopted because it is underpinned by the belief that data *and* theories are constructed. From this standpoint, data are jointly constructed by the participant and researcher, and the theory that results from the analysis is an '*interpretive* portrayal of the social world, not an exact picture of it' (Charmaz 2006: 10 original emphasis).

Ethical approval was granted by the Centre for Criminology and Sociology's departmental ethics committee at Royal Holloway, University of London's prior to beginning data collection. In line with this approval, participants and their family members are referred to using pseudonyms to maintain their anonymity.

Below, we report the findings from the study. We start by clarifying the contradictions posed by the diet and defining the 'good parent' as a concept derived from parents' discussions. Following this, four techniques used by parents to manage their identities are outlined. Two of these techniques were particular to the ketogenic diet (Food as Medicine and Fat as Good), while the other two have been more commonly discussed in the literature on food and parenting (Food as a Symbol of Inclusion and Food as a Symbol of Love).

Findings

The main contradictions presented by the diet were that it was high-fat, portion sizes were small and the child was often unable to eat the same food as their family members and peers, thereby contradicting the feeding norms associated with parenting, described above. Parents drew on the concept of the 'good parent' to overcome these contradictions and to help manage their identities. It is acknowledged that notions of good parenting vary between groups and change over time (Lee et al. 2014). Here, it is the participants' perceptions of good parenting that are presented. Parents felt they could overcome some of the contradictions outlined above by altering the meanings attached to foods or by selecting foods that adhered to one or more of the food norms related to parenting (e.g. providing adequate

portion sizes and ensuring children enjoy their food). The following two sections describe two interrelated adjusted meanings associated with the child's food.

1) 'Food as Medicine'

The first way parents overcame some of the contradictions presented by the diet is described by Naomi in the following quotation:

I do sometimes think 'oh, I should really give her more variety'.
But you kind of have to start thinking of food as medicine. You
don't have to have too much emotion attached to it.

DeVault (1991) notes that norms related to feeding others tend to be referred to more directly when people feel that they are unable to follow these norms; a feature which was common in parents' discussions about the diet. Indeed, this is what Naomi is doing here when she acknowledges the importance placed on consuming a varied diet. However, Naomi then describes how she overcame this contradiction – by viewing food as medicine. It is acknowledged that medicines are not always viewed positively (Britten 2008); however, in this instance, parents used this terminology to express the beneficial impact this treatment was having on their child.

This view of food as medicine is in stark contrast to Veen et al.'s (2013) research on families with a child with coeliac disease, where it was found that dietary alterations were demedicalised. Instead, parents in this study drew on the medical model – the dominant approach to illness in Western society that assumes an underlying pathological cause of illness and gives authority, regarding the diagnosis and treatment of illness, to those in the medical profession (Bury 2013). Drawing on this model enabled parents to view food functionally in the sense that they saw the entirety of the child's food consumption as a treatment for their condition. Naomi described how, by viewing food in this way, some of the meanings and norms attached to food became irrelevant. Indeed, when these norms were stripped away, the child's food could be thought of purely in terms of

the benefit this dietary treatment was having; all parents had seen a reduction in their child's seizures, many described other benefits such as increased alertness and some had been able to reduce the child's medication and felt this had resulted in fewer side effects. These benefits undoubtedly contributed to the good parent identity as parents were providing an effective treatment for their child's epilepsy.

When speaking about creating meals, parents tended to talk about the child's food in a scientific way. Parents often spoke about the child's 'prescription' – the amount of fat, protein and carbohydrate each meal had to contain – again linking to the idea of food as medicine. Below are quotations relating to the three different diets that illustrate the way in which food was spoken about. The type of diet being referred to is given in brackets at the end of each statement.

Paul: He's on a 4:1 ratio. (Classical)

Hannah: We've just tweaked the diet again, so at the minute it's 29 fat [points] and we're up to 9 carbs. (MAD)

Kelly: When we started he was on 16 exchanges a day. And ... 81 units of MCT. And ... 6 of those 16 [exchanges] needed to be protein sources. (MCT)

The classical version of the diet was spoken about using ratios of fat to protein and carbohydrate, and the MAD and MCT diet were thought of in terms of exchanges or points relating to each food type (fat, protein and carbohydrate). Chowdhury et al. (2000) note that, unlike nutritionists, lay people rarely classify foods into these types; however, these parents regularly talked about food in this way. It is likely that speaking about food in these terms is a form of 'cultural health capital' (Shim 2010) that parents had developed through their regular interactions with dieticians. However, this did not appear to be class specific, as the two working class parents also drew on this discourse.

The extent to which parents were able to view food as medicine varied between families, but for many it was a practical way of overcoming

some of the contradictions presented by the diet. Parents who were able to view food primarily as medicine were those who had been using the diet longest and those whose children were young or had co-morbidities or learning difficulties associated with their epilepsy. Some of the children's learning difficulties resulted in them not being particularly interested in food; therefore, parents did not feel they were depriving their child of foodstuffs they wanted. Equally, children who were younger often did not compare their food to others' food consumption; this meant they did not feel they were missing out, which again meant parents did not regularly feel guilty when implementing the diet.

It has been noted that viewing food as medicine is common in many cultures (Helman 2007). In the UK the health promoting properties of vitamins began being advertised during the 1920s and influenced the way in which the nation viewed food (Horrocks 1995). This change in attitudes resulted in certain foods being seen to have medicinal value. Although the perspective of parents in this study is similar in that they also linked food and health, it differs because rather than specific foods, *all foods* the child consumed were seen to have medicinal value.

As a result of coming to view the child's food as medicine and by focusing on the purposeful aspect of the diet, a further new meaning was attached to the child's food – fat came to be seen as good.

II) Fat as Good

Interestingly, despite the negative meanings that are normally attached to fat (Lupton and Chapman 1995; Lupton 1996, 2005; Counihan 1999; Saguy 2013) and the importance placed on feeding children a 'healthy' diet (Cook 2009a, 2009b; Stapleton and Keenan 2009), the high fat content of the diet was not something that parents found problematic. This can be explained by the fact that parents had started to view food as medicine and were focusing on the benefits this 'medicine' was having for their child; in so doing they were able to reverse the negative meanings attached to fat and fatty foods. For example, when speaking about choosing different products Jane said, 'the more fat the better'. This is not a statement a parent would

typically make in relation to their child's food consumption. However, it was echoed by a number of parents who said that they checked product labels and sought out those with the highest fat content.

Similarly, a number of parents spoke to their children about 'the magic diet'. In the extract below, Jessica is describing how the staff at her son's new school told him not to drink the oil that was left when he had finished his salad.

He even told me that the other day he wanted to drink his salad sauce and then they said 'no, no, no. Just leave it'. So I'm going to have to tell them tomorrow 'no, that's the magic ingredient in that sauce'.

Again the term 'magic' is used in relation to the diet and, most importantly, the fat content of the food. This phrase was most commonly used to emphasise the positive impact of the diet, and particularly the high fat content, to children and those unfamiliar with the diet. However, it also illustrates the positivity with which parents viewed the diet as it was felt to have improved their child's quality of life to a far greater extent than other previous treatments. Furthermore, the above extract illustrates that views of fat had been altered in these families and that there was perceived to be a need to educate others appropriately on the importance of administering the child's 'medication' correctly.

This positive view of fat helps to explain why parents did not find implementing a high fat diet emotionally troubling; by seeing fat as good they could view themselves as good parents because they were feeding their child 'good' foods. Indeed, a number of parents described the diet as healthy:

Ellen: I *really* do think it's a healthy diet. You're burning off fat quickly and you're getting the right amount of calories. It's weighed, it's to the gram. And she's getting a whole range. And she looks perfectly healthy on it.

The above discussion has illustrated that families using the ketogenic diet came to see food as medicine and fat as good. However, some meanings

usually attached to foods remained unchanged and the child's food was adjusted in accordance with these norms. Although it was shown above that by viewing food as medicine parents were sometimes able to see food in a functional way, their emotions could not always be separated from feeding their child.

III) Food as a Symbol of Inclusion

The third way parents were able to construct themselves as good parents was to use food as a symbol of inclusion. It has previously been argued that food is an important feature of family life as it symbolises cohesion or inclusion within a particular group (James *et al.* 2009; Stapleton and Keenan 2009). This meaning was consistently drawn upon by parents when discussing what their child ate, when and with whom.

Special occasions or family events were common situations for parents to use food in this way. For example, Jane organised a ketogenic birthday party for her son where all the children were eating essentially the same foods. In other families, rather than being the same, foods just had to have a similar appearance. For instance, Hannah explained:

We went to my step-Mum's for Easter and she did a ketogenic meal ... It's egg whites all beaten up and that's his. And she puts some little berries on it ... and that's his pudding. So then everybody else had pavlova so it all looked the same colour ... And then the dinner itself, some of the kids didn't have starters so that wasn't a big deal. And then the main meal, his was all cut up and mixed up together, so was Alfie's [sibling] so that's just how Granny did it for both of them.

As Hannah notes, using food in this way was intended to include the child in events surrounding food in the same way as their siblings and/or peers.

Rather than foods just having a similar appearance, a further way of including children was to create ketogenic alternatives to the foods being consumed by others. Common alternatives included sweets, chocolate, cake and other foods that are usually seen as treats. For example, Hashani said:

Lately, because it's been the summer and her sister has been having ice cream and lollies from the freezer I've started making

her keto lollies, which she really likes. And again, they'll sit and have those together, which is really nice.

Significantly, as in Hashani's statement above, these alternatives tended to be given at times when siblings or peers were eating these foods. This meant that parents could feel they were treating children equally and that the child on the diet was included.

In some instances, parents would make ketogenic alternatives for entire meals. Two parents who went to great efforts to create alternatives of many meals were Paul and Alison. They explained that the diet had initially challenged their parenting identities, as they had felt guilty eating in front of their son.

Alison: I think at first it was quite, it was the guilt. You know, we're sat here eating a Yorkshire pudding and a roast potato...

Paul: With these big beady eyes looking at you and you're thinking 'I can't cope with this'.

Alison: Yeah. At the beginning we never ate together, did we?

Paul: No, no.

Alison: Because we felt too guilty knowing that he couldn't have...

Paul: What we were having.

Alison: Things that he loved. He loves food.

However, they then explained how they felt it was important for them to move past feeling guilty because it was vital that meal times were social times. They described how they restored their good parent identity by creating ketogenic alternatives of meals so that their son felt included. On the evening of the interview Connor, who was on the diet, and his older brother Joel ate Bolognese together. Joel had pasta and Bolognese and Connor had meat and vegetables in a butter and tomato sauce. Importantly for this family, they referred to both meals as 'Bolognese'. As well as parents creating ketogenic alternatives, some also modified their food consumption and ate certain meals more frequently so the child on the diet could eat something similar.

Not all parents used ketogenic alternatives to encourage their child to feel included; however, the majority of them did ensure the child ate at the

same time and in the same place as others. Like Paul and Alison above, many parents felt meal times should be sociable events and that children should never eat alone. For instance, although Hashani's daughter often ate before the rest of her family to ensure her meals were evenly spaced, she was still included in the evening family meal.

Hashani: We did try giving her food at the same time as us. She just plays with it and throws it around. So what we do, we'll give her some salad or some vegetables so that she's at the table. Or even just an empty plate with a knife and fork. [Laughs] ... Yeah, she'll sit with us.

Therefore, many parents still felt they were able to have family meals, even if they were eating different foods, because they could eat together. Alternatively, as in the example above, just the presence of all family members was enough for some to consider the meal a social event that included everyone. Additionally, parents' prioritisation of family meals reinforces the argument that parents still attach much significance to the 'family meal' (James et al. 2009; Stapleton and Keenan 2009). Importantly, parents could view themselves as good parents because they were able to uphold this norm whilst implementing the diet.

However, parents did alter some norms surrounding eating practices. For example, family members did not share their food with the child on the diet. Equally, these children were taught not to share their food:

Peter: There were little games that we played ... We made her pancakes at breakfast and said 'oh, that looks lovely. Can I have some?' 'No. It's mine'. So that possessiveness about her diet ...

Ellen: It was *her* diet.

Peter: It was her diet. No one else could eat it.

Despite this alteration to eating practices, parents were still able to use food in other ways to ensure the child was included. A further meaning that was not changed as a result of using the diet was that food was seen as a symbol of love.

IV) Food as a Symbol of Love

Many of the decisions parents made in relation to the child with epilepsy's food involved prioritising either the child's enjoyment of food or larger portion sizes, both of which were ways of giving to children and using food to symbolise love. Consequently, parents could feel they were being good parents by providing for their children in these ways.

There was no specific hierarchy between norms relating to portion size and the child's enjoyment of food; instead parents drew on these norms in different instances. For example, in the extract below, Kelly is explaining that she had made her son a ketogenic birthday cake but would not be doing so again in the future because he was allowed such a small portion.

He's always loved chocolate cake so we thought for his birthday last year we'd try that, and he did eat it but the amount he could have of the cake was, I don't know, the size of a small matchbox. It just was tiny ... it was about 2 or 3 exchanges for this tiny bit. Whereas, I said to my husband that he loves pears, he loves strawberries, you can get tons of pear and tons of strawberries for that. And you could put some cream on it. You could put sweetener in the cream.

Kelly initially drew on norms related to showing love by providing children with foods they enjoy (Lupton 1996). However, she justified her choice of not repeating this in future and showed her love for her son by prioritising portion size instead. This discursive reasoning is similar to the reconciliation of repertoires described by Will and Weiner (2014). In their research on cholesterol-lowering foods they found that people drew on the repertoires of health, pleasure, sociality and pragmatism when speaking about their food choices. Drawing on these categories, here the discussion of norms relating to portion size and the child's enjoyment of food both relate to the repertoire of pleasure; however, they appear to constitute separate and distinct repertoires in this context.

Small portion sizes were something that parents often tried to compensate for in different ways. For example, Jessica said, 'we have these tiny dishes that make it look like a lot'. And, like Kelly above, many parents talked about how they would choose one food over another because it

appeared to be a larger portion. These examples illustrate that parents found small portion sizes challenging to their parenting identity and had found different ways to overcome the problem, enabling them to feel they were being good parents.

However, portion size was not always given priority when parents made choices associated with the child's food consumption. In the extract below Kelly is explaining why she opted for her son to go on the MCT diet over the classical version of the diet.

In general as he's got a bit older he enjoys food. So I didn't want to take that away from him and I wanted to keep him eating things that he enjoyed eating, even if it was less.

Here Kelly constructs herself as a good parent by explaining she chose not to deny her son food he enjoys and that this was given priority over portion size. Similarly, Hashani drew on the importance of providing children with food they enjoy when she commented that her daughter's meals are 'quite samey, but she really likes pizza so it's all right'.

A further way of ensuring children were eating foods they enjoyed was to give them choice over their food consumption. For example, Jane said:

I do tend to give him quite a choice a lot of the time and say 'look, we're having this. What do you want?' Because I think he should have a bit of a choice really because he doesn't have a lot.

Jane's extract suggests that she may have felt guilty about the limited range of food her son could eat, so she compensated for this by allowing him to choose his meals from the available options.

Therefore, at times, parents adjusted the child's food in order to conform with norms relating to portion size and feeding children foods that they enjoy and thus were able to feel they were being good parents. By prioritising these different norms parents were using the child's food as a symbol of love.

Discussion

The findings presented above support the fundamental argument in the sociology of food literature that food has intrinsic social functions and meanings attached to it (DeVault 1991; Beardsworth and Keil 1997; Delormier et al. 2009). Despite the nature of the ketogenic diet, food was still seen to symbolise inclusion and love. However, this research has also shown that although the meanings attached to foods are ingrained and difficult to challenge, they are not fixed. By coming to view food as medicine parents were able to reverse the negative meanings attached to fat. It could be argued that potentially this was one of the most difficult meanings to alter given the current, and prolonged, emphasis on reducing dietary fat in health promotion campaigns (Blank et al. 2009). This adjustment of meaning suggests that the meanings attached to foods are malleable and may be altered if food is used as a medical treatment. As was the case in this study, the meanings attached to food may be more likely to be altered if dietary treatment is successful when previous treatments have had limited efficacy.

It has also been shown that the inherent nature of the ketogenic diet may be problematic for parenting identity. For instance, denying children food (either types or quantities) can lead to parents feeling guilty. However, by being creative with food choice parents were still able to use food to symbolise love and inclusion and construct themselves as good parents. Within this sample, success on the diet also contributed significantly to the good parent identity, as parents felt they had been able to increase their child's quality of life when previous treatments had not been effective. As the views presented above relate only to families who have had success with the diet, additional research is needed to understand the views of parents who find the diet is ineffective and those who choose not to continue implementing it despite efficacy.

It has been illustrated here that the norms relating to child feeding practices do not have a set hierarchy. In this instance norms associated with portion size and the child's enjoyment of food were given priority at different times to justify food choices. This is similar to what Will and

Weiner (2014) describe as reconciling repertoires. It has been argued that these norms constitute different repertoires in this context as parents drew on them at different times to justify the choices they had made. Therefore, the norms individuals draw on are likely to be closely linked to the diet under discussion.

It has previously been found that class differences influence parents' child feeding practices (Backett-Milburn et al. 2006; Wills et al. 2011); however, here, although the sample was not particularly diverse, class did not appear to impact on the meanings parents attached to ketogenic foods. In relation to food as medicine, acquired cultural health capital (Shim 2010) gained from interactions with dieticians could be one reason for this. A further reason could be that these parents were united by being able to provide a successful treatment for their child's epilepsy. However, as the participants in this study were predominantly white, mainly from the top quartile of earners and from two-parent families, additional research would be required to assess whether the findings are applicable to other social groups or family formations. Furthermore, within this paper parents have been addressed as a homogenous group because the meanings attached to foods and the identity management techniques used applied to all participants. Any gender differences in the food work taken on by parents will be the focus of another paper.

This research has added a new dimension to the literature relating to how families manage dietary change for medical reasons. Previous studies found that when one family member had been recommended dietary alterations for medical reasons, other family members often made the same changes (Kelleher 1988; Maclean 1991; Gregory 2005; Pitchforth et al. 2011). Although this study supports this finding to an extent – parents sometimes chose not to eat particular foods in front of the child on the diet – it has also been shown that family members are not always able to adjust their food consumption in line with the recommended diet. Indeed, it was found that when parents were unable to take on the same dietary alterations, many used other techniques to adapt to these changes. For instance, families were able to create ketogenic alternatives of the foods

being consumed by others, showing that the diet may be manipulated to fit in with family members' consumption patterns, as well as others' food consumption being altered to suit the diet. The ways in which families adapt to dietary changes, therefore, may vary depending on the nature of the diet.

Furthermore, in contrast to Veen et al.'s (2013) research, the diet was not demedicalised; in fact parents drew heavily on the medical model in their explanations of the diet and food choice. This difference could be explained using Shim's (2010) concept of cultural health capital. Indeed, parents may have developed this way of speaking and thinking about food through their frequent interactions with dietitians, particularly during the first few months of implementing the diet. The frequency with which people interact with dietitians may therefore help to explain the extent to which a diet is medicalised within the family.

Overall, it has been demonstrated that parents drew on the meanings attached to foods in order to manage their identities. Parents came to view food as medicine and, as a result, saw fat as good. Their success with this dietary treatment and their ability to improve their child's quality of life overwhelmingly contributed to the 'good parent' identity. Parents also prioritised portion size and the child's enjoyment of food to rationalise their decisions, resulting in parents feeling they were still able to show their child love through the food they provided. Furthermore, parents created ketogenic alternatives to include children in social situations, which again enabled them to feel they were being good parents. These important identity management techniques helped parents to construct themselves as good parents despite the contradictions presented by the diet in relation to feeding norms associated with parenting.

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Notes

- 1 Ketosis is a metabolic state where the body uses ketones rather than glucose for energy.

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