Childhood epilepsy in contemporary society: risk perceptions among children and their family members

Michelle Webster

Department of Law and Criminology, Royal Holloway, University of London, UK

Michelle.Webster@rhul.ac.uk

Although uncertainty is a key characteristic of epilepsy, and despite the close relationship between uncertainty and risk, our understanding of individuals’ experiences of childhood epilepsy in relation to risk is limited. In this paper I explore family members’ perceptions of the risks associated with the condition by drawing on qualitative data collected during 2013 and 2014 from 24 families with a child with epilepsy (including data from 28 parents, 13 children with epilepsy and 14 siblings). The diagnosis of childhood epilepsy provided parents and children with a new framework that they used to evaluate risks posed by the physical environment. Indeed, roads, water and heights were reconceptualised when viewed through an ‘epilepsy lens’ and were seen to present more risk to the child with epilepsy in comparison to the level of risk the same hazards posed to their siblings or peers. Furthermore, while parents described prioritising new and reconceptualised physical risks to their child, the children with epilepsy were more concerned about being stigmatised by their peers. The children’s discussions surrounding stigma suggest that this results from interactions with their peers, rather than stigma being learnt within the family, as previous studies have suggested. Overall, I demonstrate that risk is a central feature of contemporary experiences of epilepsy for children with the condition and their parents, but that parents and children perceive and prioritise risks differently.

Keywords: epilepsy; children; risk; stigma; parents

# Introduction

The clinical literature on the diagnosis of epilepsy (Alarcón, 2012a), timing of symptoms (Baker, 1997) and prognosis (Sheth, 2002) highlights the uncertainty associated with living with the condition. However, despite the close relationship between risk and uncertainty, our understanding of individuals’, and particularly parents’ and children’s, perceptions of risk associated with the condition is limited. Furthermore, with children being constructed as a particularly ‘at risk’ group in contemporary society (Firkins & Candlin, 2006; Jackson & Scott, 1999; Lee, Macvarish & Bristow, 2010; Lupton, 1999; Meyer, 2007), a fruitful area for exploration is how perceptions of the condition and notions of childhood interact in individuals’ discussions of the risks associated with childhood epilepsy. Consequently, in this paper I aim to detail the extent to which risk featured in children’s and parents’ descriptions of everyday life with the condition and whether their perceptions of risk aligned.

First, I provide an overview of the existing literature on experiences of daily life for those with epilepsy and contextualise the findings by exploring the relationship between children and risk in contemporary society. I then detail the qualitative approach used to gather the data, which included group interviews, semi-structured interviews with parents and individual photo-elicitation interviews with children with epilepsy and their siblings. The analysis of the data revealed that all family members perceived there to be risks associated with the condition and many participants described reconceptualising risks in light of the child’s diagnosis. However, children and their parents prioritised different types of risks; while the parents focused on physical risks associated with epilepsy, the children described being more concerned about being stigmatised by their peers.

## Living with epilepsy

Epilepsy is a chronic condition characterised by a propensity towards epileptic seizures (Alarcón, 2012a), which are caused by abnormal electric activity in the brain and can take a variety of forms, some of which include a loss of consciousness (Alarcón, 2012b). An identifiable cause of the condition can only be found in 30% of people (Alarcón, 2012a) and just a small proportion of people’s seizures are brought on by certain stimuli, known as triggers (Alarcón, 2012b). Consequently, the majority of people’s seizures are unpredictable and occur spontaneously (Baker, 1997). While for some this will be a lifelong condition, ‘benign’ forms of epilepsy are age-specific and seizures will cease during childhood or adolescence (Sheth, 2002).

As a result of this clinical manifestation, there are significant uncertainties inherent in living with epilepsy. For adults with the condition, the uncertainty related to the timing of seizures is most troubling (Scambler, 1989). Indeed, the possibility of seizures means that periods of time without symptoms are just as dictated by the condition as times when they occur (Reis, 2001).

Risk as a theoretical framework was derived inductively from the data (which is explained below in more detail below), but the high levels of uncertainty associated with experiences of epilepsy makes the applicability of this framework somewhat unsurprising. While uncertainty alone does not necessitate a risk response (Zinn, 2008), risk is bound to notions of uncertainty. Indeed, risk now refers to any *possible* unwanted outcome, as opposed to being a neutral term used to express calculable probabilities (Lupton, 1991; Fox, 1999). As explained by Lee, Bristow, Faircloth and Macvarish (2014):

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. (p. 11 original emphasis)

What this demonstrates is that uncertainty regarding a possible or probable future occurrence is a central element in perceiving risk. The second key aspect in defining risk, as it is used here, is that the uncertainty relates to a perceived future harm. Indeed, in contemporary society, risk is seen as being synonymous with danger, threat and hazard (Lupton, 1991; Fox, 1999).

Building on this definition of risk, I adopt a weak constructionist approach to risk (Lupton, 1999), as the focus of this paper is the social construction of perceptions of risk. Here, risk and uncertainty are differentiated as follows: uncertainty is something that is experienced, whereas risk is something that is perceived. Although uncertainty is central to perceptions of risk, an in-depth exploration of family members’ experiences of, and responses to, uncertainties is presented elsewhere (Webster, 2016, 2019), as is an overview of the ways in which different family members managed risks (Webster, 2016).

While there is a wealth of literature on epilepsy and risk factors relating to, for instance, SUDEP (Sudden Unexpected Death in Epilepsy), onset of the condition, and development of anxiety and depression associated with it (see for example: Monté, et al., 2007; Hesdorffer, et al., 2011; Ekinci, Titus, Arman Rodopman, Berkem & Trevathan, 2009), there is much less written on the topic of individuals’ perceptions of risk. Tonberg, Harden, McLellan, Chin and Duncan (2015) have explored young adults’ perceptions of the risk of SUDEP, while Elliott and Long (2008) looked at perceptions of risk associated with driving among those with epilepsy. However, as Green (2009) has noted, when people are asked specifically about ‘risk’, we are likely to gather data on risk, rather than exploring whether, and if so the extent to which, individuals themselves think in terms of risk. Furthermore, quantitative studies, such as Elliott and Long’s, impose risk upon the data, rather than being steered by participants’ views. Consequently, there is still space to utilise sociological understandings of risk when exploring perceptions of risk associated with epilepsy, particularly within familial units.

As well as uncertainty and risk, the existing literature suggests that stigma – defined by Goffman (1963) as a discrediting bodily feature, behaviour or demographic characteristic – is another defining feature of living with epilepsy. Indeed, many adults with epilepsy believe that the condition is stigmatised (Scambler, 1994; Scambler & Hopkins, 1986, 1988; Schneider & Conrad, 1983). Although the overall trend has been for a reduced level of stigma being attached to epilepsy over time (Jacoby, Gorry, Gamble & Baker, 2004; Scambler & Hopkins, 1986; Shostak & Fox, 2012), there is evidence to suggest that people with epilepsy still experience stigma (Jacoby & Jacoby, 2004).

Furthermore, despite reduced levels of stigma, many people with epilepsy continue to *feel* stigmatised as a result of the condition (Scambler, 1994). Scambler and Hopkins (1986, 1988) built on Goffman’s (1963) iconic 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.

For those who feel stigmatised by the condition, seizures and the label of epilepsy can have a profound impact on the self. Adults with epilepsy in America saw seizures as a threat to, and in some cases a suspension of, the self (Schneider & Conrad, 1983). Additionally, Schneider and Conrad (1983) argued that the stigma associated with epilepsy meant that people carried the burden of feeling that they were in some way ‘spoiled’.

The majority of the sociological research carried out on epilepsy has considered the experiences of adults with the condition (see for instance: Conrad, 1985; Scambler, 1989; Scambler & Hopkins, 1986, 1988; Schneider & Conrad, 1983; Shostak & Fox, 2012). Although some of these studies report the experience of epilepsy during childhood, these descriptions are based on adults’ memories. As children’s experiences and adults’ recollections of their childhoods do not always equate (Hockey & James, 1993), adults’ accounts of epilepsy during childhood may not be an accurate representation of children’s experiences of living with the condition. Furthermore, experiences of chronic conditions vary over the life course (James & Hockey, 2007), which raises questions regarding how children experience living with epilepsy.

Although the experience of epilepsy during childhood is understudied, there is some evidence to suggest that children’s experiences of the condition may align with those of adults. For instance, children in the UK have described feeling different from others and from a previous self (Weinbren & Gill, 1998), indicating that, much like adults, children can also feel stigmatised by the condition. Furthermore, some young people in Scotland felt embarrassed as a result of their symptoms (Moffat, Dorris, Connor & Espie, 2009), while children in Taiwan were frustrated because the visibility of some types of seizures meant that they were unable to selectively disclose to others (Chen, Chen, Yang & Chi, 2010). Additionally, children and adolescents with epilepsy in Italy explained that they felt vulnerable as a result of the condition because the occurrence of seizures disrupted their trust in their bodies (Galletti, Rinna & Acquafondata, 1998). This sense of vulnerability may suggest that children feel at risk due to their condition. Consequently, within this paper, I will explore the extent to which the notion of risk featured in children’s descriptions of their daily lives.

## Childhood and risk

‘Childhood’ is a social construct (Hockey & James, 1993; James, Jenks & Prout 1998; Prout & James, 1997) that did not exist in Western cultures prior to the Middle Ages (Aries, 1962 cited in Jenks, 1996). Furthermore, ideas surrounding childhood have not remained consistent; it was only during the 18th and 19th centuries that the notion of childhood as a time of innocence developed and became a dominant ideology (Hockey & James, 1993).

Within the sociology of the family, scholars have drawn upon Giddens’ (1991) and Beck’s (1992) arguments regarding risk consciousness and argued that because children are viewed as innocent, they are also seen to be a particularly vulnerable group and are, consequently, often categorised as ‘at risk’ (Firkins & Candlin, 2006; Jackson & Scott, 1999; Lee, Macvarish & Bristow, 2010; Lupton, 1999; Meyer, 2007). This conceptualisation of children has consequences for parents who are now considered to be responsible for protecting their children from risks (Jackson & Scott, 1999; Lee, Bristow, Faircloth & Macvarish, 2014).

The existing literature indicates that parents perceive there to be risks associated with epilepsy and that they attempt to manage these by making adjustments to their parenting practices. For instance, Oostrom, Schouten, Kruitwagen, Peters and Jennekens-Schinkel (2001) found that of 69 parents whose child had been diagnosed with epilepsy in the previous 48 hours, almost half (48%) felt that they could not maintain some of their current parenting techniques. Indeed, as children’s seizures are unpredictable, their parents may supervise them to a greater extent than they would their siblings or peers (Reis, 2001).

Furthermore, parents have also been found to believe that there are social risks for the child and other family members resulting from the condition. Parents felt that epilepsy was stigmatised and managed this risk using concealment; for instance, by avoiding situations where the child’s condition may be exposed (Scambler, 1989; Scambler & Hopkins, 1988; West, 1990). However, these studies are now dated and Weinbren and Gill (1998) have argued that although children wanted to conceal their epilepsy, parents tried to encourage them to be open about their condition. More recently, Kanemura, Sano, Ohyama, Sugita and Aihara (2016) found that parents’ perceptions of stigma increased when their child experienced at least one seizure per month, suggesting that the perceived risk of stigma may not be consistent among all parents, but instead might be related to the nature of the child’s condition.

Although changes in parenting practices can be interpreted as resulting from parents’ views regarding the risks associated with childhood epilepsy, there is limited research exploring the way in which a child’s diagnosis of epilepsy shapes children’s, parents’ or other family members’ perceptions of risk, or whether their perceptions coincide. Consequently, I intend for this paper to contribute to current research on perceptions of risk by exploring whether there is alignment between children’s and parents’ perceptions of the risks associated with a particular chronic condition.

# Methodology

A qualitative approach was taken in order to explore, in detail, the perspectives of children with epilepsy and their family members. More specifically, a range of semi-structured interviews were used, as their flexibility meant that the interviews could be tailored to the different groups of participants – children with epilepsy, siblings and parents. This allowed the participants to steer the interviews and speak in depth about their lives (Byrne, 2004).

The research was advertised through seven UK based charities during 2013 and 2014. The charities placed adverts on their websites, online forums, social media pages, and in their newsletters. All those who volunteered to take part in the study were included in the sample and the research was re-advertised and data were collected until saturation point was reached. In total, 24 families took part in the research. In 14 of these families the child with epilepsy was being treated with medications and in the other 10 the child was being treated with a combination of medications and the ketogenic diet. (For more information on the use of this diet see Webster & Gabe, 2016).

In total, 28 parents (24 mothers and 4 fathers), 13 children with epilepsy and 14 siblings participated in the research. These families were living in households that ranged in size from three to six people. The majority were two parent families, two of which were stepfamilies, and two were single parent families. The majority of parents self-defined as White British and only two families that provided data had an income below the national average. Nine of the children with epilepsy were male, four were female and they ranged in age from five to 13 years. Five of the siblings were male, nine were female and they ranged in age from six to 16 years.

In the families using only medications for treatment, firstly, a group interview with the parent(s) and their children was conducted. In total, 14 of these were carried out and 14 mothers and two fathers participated; in one family the child with epilepsy did not participate and in another the sibling did not take part. Group interviews were included so that the children could to get to know me before their individual interviews. Individual interviews were also conducted in order to give family members the opportunity to talk about their experiences in a more private setting. Semi-structured in-depth interviews were carried out with one or both parents in 13 of these families and lasted between half an hour and two hours. Lastly, autodriven photo-elicitation interviews were conducted with the children; 10 children with epilepsy and 10 siblings participated in this stage of the research and their interviews lasted 20 minutes on average.

The children’s interviews included a task in order to engage them and provide a stimulus for discussion. The children were given a single-use camera each and were asked 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 age of the children and young people participating in the study varied considerably and, consequently, this methodological technique was chosen as it had been successfully employed with those aged 3-17 years (Cook & Hess, 2007; Croghan Griffin, Hunter & Phoenix, 2008). Furthermore, Zartler and Richter (2014) argue that children find it easier to talk about topics when they have a visual prompt and Cappello (2005) found that children give more elaborate responses when they have photographs to refer to. The photos were not analysed, rather they were used to guide the interview; 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. The researcher also used an interview guide to ensure that similar topics were covered in each interview. (For detailed reflections regarding the use of photo-elicitation interviews with children see Webster, 2017).

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 in these families, one in-depth semi-structured interview was conducted in each family. In total, 10 were conducted and 10 mothers, two fathers and one sibling participated.

All interviews were audio-recorded and transcribed *verbatim.* The data were then coded using NVivo and analysed using a constructivist grounded theory approach (Charmaz, 2006). Codes which captured the meaning in the participants’ speech were inductively developed and I used the constant comparative method as I worked through the data line by line. Throughout the coding process I also wrote memos describing my thoughts on the developed codes and how they related to each other. Through the process of coding and memo writing, gaps in the developing theories emerged and I was able to purposefully collect data to fill these gaps. Data collection continued until categories became ‘saturated’ (Charmaz, 2006).

Ethical approval was granted by the Centre for Criminology and Sociology’s departmental ethics committee at Royal Holloway, University of London prior to beginning the data collection. Each child participating in the study was sent an age appropriate information leaflet and consented to their involvement in the research. The children were also given copies of their photos as a thank you for their participation. In line with the ethical approval, participants are referred to using pseudonyms to maintain their anonymity. I report the findings of the study below and where extracts from the children’s interviews are used or children are referred to, their age is given in brackets.

# Findings

The aim was to explore family members’ experiences of living with epilepsy in contemporary society and they were not directly asked about risk during the interviews. Indeed, they were asked very open-ended questions, such as ‘how does epilepsy affect your life?’ and ‘how do you manage the condition on a daily basis?’ Consequently, it is not that the theoretical framework shaped the data, which is one criticism directed at some working in paradigms of risk (Green, 2009); rather, risk emerged inductively during the analysis process as a result of the participants’ use of language when discussing the condition. For instance, when Kate was asked whether there was anything her son, Max (7), could not do because of his epilepsy she replied:

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.

Kate introduced the notion of risk in order to explain why she chose to restrict her son’s use of his bike in particular settings due to his epilepsy.

When parents spoke about risks they often used phrases such as ‘chance of …’, ‘possibility that…’, ‘if…’ and, similarly to Kate, the term ‘risk’ itself, to denote the uncertainty inherent in discourses surrounding risk. Further to the uncertainty in the risks discussed, parents also used words such as ‘dangerous’, ‘scary’ and ‘worrying’ to highlight the hazardous nature of the risks being spoken about. In line with the definition of risk outlined towards the beginning of this paper, Kate’s use of the word ‘if’ in the extract above related to a possible future occurrence. She also alluded to that future occurrence being a negative one. Combined, she was referring to a possible or probable negative future event centred around her son’s condition, his daily activities, and the location in which these activities took place, which culminated in her perceiving risk in this scenario.

The majority of parents talked about physical risks resulting from their child’s 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 being excluded socially as a result of the stigma that they perceived to be attached to the condition, but it was the children with epilepsy for whom this was a primary concern.

## New physical risks

The risks that parents described as resulting directly 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 (10)] 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 that 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 families explained that they worried about the possibility of SUDEP. For example, Ruth commented ‘because of the risk of SUDEP she’s [Alice’s (12)] monitored 24 hours a day’. Again, Ruth used the term ‘risk’ to denote both the uncertainty inherent in perceptions of risk and the potentially fatal consequences of epilepsy.

Furthermore, parents in 16 families were concerned about their 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 (8)] 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.

Catherine’s repetitive use of phrases such as ‘really bad’, ‘scary’ and ‘dangerous’ in the extract above clearly demonstrate the severity of the risk she associated with *status epilepticus,* which was echoed by other parents. Furthermore, this illustrates that parents’ perceptions of risk were socially constructed and, in part, influenced by their previous experiences. Similarly to Catherine, parents often explained their views on risk by drawing on past experiences to illustrate the potential harmful or fatal consequences of such occurrences, but also that these occurrences were possible or probable.

In parents’ narratives, perceptions of new physical risks were often particularly high around the time of onset and/or diagnosis of the condition. Indeed, three parents made comparisons between caring for their newly diagnosed child and caring for an infant. For instance, Carol said:

I wouldn’t be able to sleep because I’d be staring at her [Rosie (9)] thinking ‘oh’, you know, sort of prodding her like when they’re babies, you know, prodding them to see if they’re, you know, because I was just really worried.

Similarly, Nicola commented that she felt leaving hospital with her son [Zak (13)] after he had been in intensive care as a result of his first seizure was comparable to leaving with him as a new born baby, because she felt she was suddenly left alone to care for a particularly vulnerable child. Indeed, although all children are seen to be ‘at risk’, infants are deemed to be a particularly ‘at risk’ group (Lee et al*.*, 2010). Therefore, parents clearly felt that their child’s vulnerability had increased as a result of their condition and the presence of these new physical risks.

Although parents perceived children to be exposed to numerous 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), who was the eldest child with epilepsy in the study. For instance, he commented ‘if the worst came to the worst then it could be my last day’, indicating he felt epilepsy could end his life. Zak’s use of ‘if’ and ‘could’ demonstrate the future-oriented possibility to which he was referring. It may be that some parents chose not to talk to their children, particularly younger children, about these risks in order to protect them and avoid worrying them. Sarah alluded to this when she explained a situation that occurred between her son, Chris (11), and another child in his class at school:

Very helpfully, Chris went back to school the day he was diagnosed and said ‘oh, I’ve definitely got epilepsy. I was diagnosed’. ‘You can die from that, you know’ was the response he got. [Laughs] Thank you, child.

Alternatively, it may be that the other children were aware of these risks, but they did not perceive them to be significant. If children did not introduce potential risks into the conversation they were not probed on them during the interview for ethical reasons, so it is not possible to draw a firm conclusion regarding why parents appeared to place much greater emphasis on these new physical risks.

Beyond the risks that were exclusively associated with the child’s condition, many parents and children felt that there was a risk of incurring injuries during seizures. Consequently, both groups tended to reconceptualise pre-existing risks when viewing them through an ‘epilepsy lens’; that is, when compared to their peers without the condition, these pre-existing risks were seen to be riskier for children with epilepsy.

***Reconceptualised 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 & 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 (8)] and Noah (5), 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, as the extracts from Kelly and Ruth in the previous subsection highlight, night time was also reconceptualised as a particularly risky time for many of the children.

Furthermore, some parents described feeling that heights posed an increased risk to their children following their diagnosis. As Heather explained:

When he [Ross (10)] first had them … she [Auntie] didn’t want him going up the stairs. You know, we were like that as well. We were, not on red alert, but just, you know, ‘you can’t climb up on that’ or ‘you can’t do that’.

Risk management techniques, such as those described by Heather, help to provide insight into parents’ perceptions of risks. Like the risk water presented, heights were deemed more hazardous for children with epilepsy than for those without the condition because, in most instances, there were no visible warning signs that the child was going to have a seizure. As Heather’s extract illustrates, one of the consequences of this reconceptualised view of risk was that limits were sometimes placed on children’s activities that had not been deemed necessary before. Furthermore, as was noted above, parents often perceived children to be at greatest risk immediately following diagnosis or after a hospital admission; this tended to reduce if the child’s seizures became less frequent.

Again because of the unpredictable nature of children’s seizures, as was noted in relation to Kate above, the risk posed by roads was often reconceptualised and seen to be heightened. For example, Anita explained:

If we get to a road I do just grab her [Lydia (12)]. But I can’t grab her hands anymore because she doesn’t like that, but I’ll grab a bit of her coat because I can’t take the chance because before she has, if she’s had a seizure she’s just carried on walking … So it’s very dangerous really.

Anita used the phrases ‘chance’ and ‘very dangerous’ to emphasise the risk that roads presented to her daughter as a result of the nature of her seizures. Furthermore, these risks had been reconceptualised, as roads would not normally have been seen to present this level of risk to a child of Lydia’s age who did not have epilepsy. Therefore, one of the primary concerns for parents when reconceptualising risks in light of the child’s epilepsy was the unpredictable nature of the condition and how seizure occurrence may interact with pre-existing risks.

Half of the children also described reconceptualising 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.

Ross’ use of the word ‘if’ denoted a possible future occurrence and he emphasised the consequence of being ‘screwed’ if this were to happen; therefore, demonstrating similar sentiments regarding risk to those that were noted in the parents’ language. Ross also talked about being ‘extra careful’ to guard against risk. 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. Alternatively, it could be that parents only begin to communicate these risks to children when they start to gain more autonomy. Other forms of risk that were discussed by the participants resulted from perceptions of stigma and difference.

***Risks resulting from stigma and difference***

There were mixed opinions among family members regarding whether epilepsy was stigmatised in wider society. Drawing on Scambler and Hopkins’ (1986, 1988) distinction between enacted and felt stigma, the children with epilepsy described the highest levels of felt stigma, while siblings were least likely to report 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 who were individually interviewed 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.

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

Harry: No.

Interviewer: 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.

These two extracts demonstrate that instances of enacted stigma impacted on the children’s perception of their condition. However, unlike the previous extracts, Harry’s explanation did not draw upon a discourse of risk; instead he said that he *knew* that he would experience enacted stigma. Consequently, the necessary element of uncertainty was missing, meaning that this did not align with notions of risk that are evident elsewhere in the data. Furthermore, this finding contrasts with previous research, where it was argued that stigma was learnt within the family (Scambler & Hopkins, 1988; Schneider & Conrad, 1980, 1983), 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, appeared not to 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 (9), did not like people realising that 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’. I interpreted the children’s reluctance to talk about their epilepsy as an indication that they felt stigmatised by the condition. However, because they did not articulate their feelings it is not possible to say whether they felt ‘at risk’ of enacted stigma. I argue, however, that their felt stigma most likely emerged as a result of interactions with their 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 who were individually interviewed said ‘no’. The other five siblings explained that their brother or sister received more attention than themselves and that they were well cared for, which was predominantly not seen to be negative treatment; although, Natalie (14) did note that well-meaning actions did not always have positive effects:

I think the school does [treat Lydia (12) 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) said that he felt his brother was at risk of being treated negatively if others were aware of his condition.

Interviewer: Do your friends at school know [Isaac (9) 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.

Interviewer: Oh OK. So that’s how your friends knew?

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

Interviewer: 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.

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

Nathan: Yeah, not really.

Interviewer: 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. This perception was what Nathan then drew upon when justifying why he chose not to explain Isaac’s seizure to his peers. Furthermore, Nathan’s use of the word ‘probably’ indicates that he thought this outcome was likely, but not certain. Consequently, even though notions of risk seem much more applicable here, only a small minority of siblings felt that 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, parents expressed mixed opinions regarding whether they thought the condition was stigmatised. Parents in eight of the 23 families described feeling that their child was at risk of social exclusion. Those who felt their child was at risk all described instances of enacted stigma; for example, four parents said that they thought that their child had not been invited to other children’s birthday parties because of their epilepsy, demonstrating how these perceptions of risk were socially constructed. Therefore, similarly to the children, felt stigma among the parents appeared to be closely linked to enacted stigma. These findings stand in contrast to previous research, which found that felt stigma was far more common than enacted stigma (Scambler & Hopkins, 1986, 1988).

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 families thought people with epilepsy often resent the condition during adulthood and described believing that 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 (8)] 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 in the future if she perceived the condition negatively.

# Discussion

This study found high degrees of risk consciousness in the narratives of parents of children with epilepsy and – to a lesser extent – in the accounts of the children themselves. An explicit language of ‘risk’ was regularly invoked by parents who referred to their child as being exposed to a number of risks as a result of their epilepsy. The children also described risks associated with their condition, but the views of children and parents did not always coincide.

Limited research has been conducted into children’s experiences of chronic conditions, especially when compared to the wealth of literature on those of adults. More, however, has been written on childhood culture. For instance, James (1993) found that children place a high degree of emphasis on ‘sameness’ and ‘conformity’. I similarly identified an emphasis on conformity, which meant that children with epilepsy often described feeling different from their peers and were at risk of being stigmatised. For many of the children, their felt stigma outweighed their fear of physical risks; that is, although some of the children talked about the risk of physical injuries were they to have a seizure – in water, near a road or were they to fall from a height, and a minority of the children talked about the possibility of death as a result of seizures – I found them to be primarily concerned about being stigmatised by their peers. This study has consequently explored how childhood culture can impact upon the way in which children perceive chronic conditions, in this case epilepsy. Yet, when compared to their parents, children drew on discourses of risk less frequently when discussing stigma. The study design does not allow us to determine conclusively whether children think about stigma in terms of risk, but this is something that should be explored in future research.

Half of the children who described feeling stigmatised as a result of the condition spoke about how these feelings developed due to their interactions with those outside the family, primarily their peers. As none of the children spoke about feeling stigmatised as a result of a family members’ actions, this contradicts earlier studies which found that parents acted as stigma coaches (Schneider & Conrad, 1980, 1983) or that stigma was learnt within the family (Scambler & 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. Conceptualisations of risk may therefore have shaped the experience of childhood epilepsy in contemporary society.

Although the children with epilepsy were primarily concerned about being stigmatised, parents’ views did not always align. Instead, parents explained that they prioritised physical risks to their child and, as a result, risks associated with stigma were a secondary consideration for parents in contemporary society. In this way, it appeared that societal constructions of children as a particularly vulnerable group (Firkins & Candlin, 2006; Jackson & Scott, 1999; Lee et al*.*, 2010; Lupton, 1999; Meyer, 2007) framed the way in which parents perceived and prioritised risks.

However, the diagnosis of epilepsy did impact upon the way in which pre-existing physical risks were perceived by both children and parents. Indeed, both groups, but particularly the parents, described reconceptualising everyday environments and activities in light of the child’s diagnosis and perceived certain hazards, for instance, heights, water and roads, to be more risky to the child with epilepsy than their peers. Backett-Milburn and Harden (2004) have previously argued that parents and children reconceptualised risk using their own ‘biographical lens’. Here, parents and some of the children were found to use an ‘epilepsy lens’, meaning that the condition shaped their perceptions of risk. Consequently, perceptions of risk were influenced by both the child’s age and their condition, with the diagnosis of epilepsy taking priority and resulting in perceptions of particular risks being heightened.

I have also shown that, for parents in particular, the diagnosis of childhood epilepsy resulted in concerns about risks that they had not previously considered. Indeed, parents spoke about their worries regarding a number of physical risks associated with the condition that they had not considered to be a risk to their child prior to their diagnosis. It is interesting that the only child with epilepsy to mention any new physical risks was the oldest child in the sample at age 13. It may be that children did not see themselves as being susceptible to these new risks. Alternatively, given that children are seen as innocent (Hockey & James, 1993) and parents are deemed to be responsible for protecting their vulnerable children (Jackson & Scott, 1999; Lee et al., 2014), parents may not have wanted to burden the children with information regarding these new physical risks. Questions that this study does not address relate to the extent to which children are given the opportunity to fully understand the conditions that they live with, and at what age children are deemed to be able to comprehend this information. Further research exploring parents’ decision making regarding the communication of risks to children would help to address these gaps in understanding.

# Conclusion

Overall, this paper highlights that risk was a key feature of the experience of childhood epilepsy in contemporary society for both children and their parents. Furthermore, by drawing comparisons with previous studies, it appears that notions of risk have resulted in a change in priorities, particularly for parents, who are now most concerned with protecting the ‘at risk’ child. However, children’s concerns did not always align with those of their parents; while parents focused on new and reconceptualised physical risks to the child, the children’s primary preoccupation was with being stigmatised by their peers. Therefore, it seems that the uncertainty that is evident in the clinical literature on epilepsy mainly influences parents’ understandings of risk, particularly new physical risks, whereas the children’s experiences were most heavily influenced by childhood culture and the fear of being marked as ‘other’ by their peers.

# Acknowledgements

I should like to acknowledge the funding received for this study from an Economic and Social Research Council CASE studentship, in conjunction with Epilepsy Action (grant reference ES/I901337/1). I am extremely grateful to the participants for giving up their time to share their experiences and to Epilepsy Action, The Daisy Garland and Matthew’s Friends for advertising the research. Many thanks also go to the anonymous reviewers and Dr Patrick Brown for their helpful comments on earlier versions of this paper.

# References

Alarcón, G. (2012a). Epidemiology of epilepsy. In G. Alarcón, & A. Valentín (Eds.), *Introduction to Epilepsy* (pp.329-331).Cambridge: Cambridge University Press.

Alarcón, G. (2012b). What is epilepsy. In G. Alarcón, & A. Valentín (Eds.) *Introduction to Epilepsy* (pp. 6-7). Cambridge: Cambridge University Press.

Backett-Milburn, K., & Harden, J. (2004). How children and their families construct and negotiate risk, safety and danger. *Childhood*, 11(4), 429-447.

Baker, G. (1997). Psychological responses to epilepsy: Their development, prognosis and treatment. In C. Cull, & L.H. Goldstein (Eds.) *The Clinical Psychologist’s Handbook of Epilepsy: Assessment and Management* (pp. 96-112). London: Routledge.

Beck, U. (1992). *Risk Society: Towards a New Modernity.* London: Sage.

Byrne, B. (2004). Qualitative interviewing. In C. Seale (Ed.) *Researching Society and Culture* (pp.179-192). London: Sage.

Cappello, M. (2005). Photo interviews: Eliciting data through conversations with children. *Field Methods,* 17(2), 170-182.

Charmaz, K. (2006). *Constructing Grounded Theory*. London: Sage.

Chen, H.-J., Chen, Y.-C., Yang, H.-C., & Chi, C.-S. (2010). Lived experience of epilepsy from the perspective of children in Taiwan. *Journal of Clinical Nursing,* 19(9-10), 1415-1423.

Conrad, P. (1985). The meaning of medications: Another look at compliance. In P. Conrad (Ed.) *The Sociology of Health and Illness: Critical Perspectives* (pp. 150-162). New York: Worth Publishers.

Cook, T., & Hess, E. (2007). What the camera sees and from whose perspective: Fun methodologies for engaging children in enlightening adults. *Childhood,* 14(1), 29-45.

Croghan, R., Griffin, C., Hunter, J., & Phoenix, A. (2008). Young people's construction of self: Notes on the use and analysis of the photo-elicitation methods. *International Journal of Social Research Methodology*, 11(4), 345-356.

Ekinci, O., Titus, J.B., Arman Rodopman, A., Berkem, M., & Trevathan, E. (2009). Depression and anxiety in children and adolescents with epilepsy: Prevalence, risk factors, and treatment. *Epilepsy and Behavior,* 14(1), 8-18.

Elliott J.O., & Long, L. (2008). Perceived risk, resources, and perceptions concerning driving and epilepsy: A patient perspective. *Epilepsy and Behavior,* 13, 381-386.

Firkins, A., & Candlin, C.N. (2006). Framing the child at risk. *Health, Risk and Society*, 8(3), 273-291.

Fox, N. (1999). Postmodern reflections on ‘risk’, ‘hazards’ and life choices’. In D. Lupton (Ed.) *Risk and Sociocultural Theory: New Directions and Perspectives* (pp.12-33). Cambridge: Cambridge University Press.

Galletti, F., Rinna, A., & Acquafondata, C. (1998). An insight into children’s and adolescents’ experience of seizures and epilepsy. *Seizure,* 7(4), 309-316.

Giddens, A. (1991). *Modernity and Self-Identity: Self and Society in the Late Modern Age.* Cambridge: Polity Press.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity.* New Jersey: Prentice-Hall.

Green, J. (2009). Is it time for the sociology of health to abandon ‘risk’? *Health, Risk and Society,* 11(6), 493-508.

Hesdorffer, D.C., Logroscino, G., Benn, E.K.T., Katri, N., Cascino, G., & Hauser, W.A. (2011). Estimating risk for developing epilepsy: A population-based study in Rochester, Minnesota. *Neurology,* 76(1), 23-27.

Hockey, J., & James, A. (1993). *Growing Up and Growing Old: Ageing and Dependency in the Life Course.* London: Sage.

Jackson, S., & Scott, S. (1999). Risk anxiety and the social construction of childhood. In D. Lupton (Ed.) *Risk and Sociocultural Theory: New Directions and Perspectives* (pp. 86-107). Cambridge: Cambridge University Press.

Jacoby, A. (1994). Felt versus enacted stigma: A concept revisited. *Social Science and Medicine,* 38(2), 269-274.

Jacoby, A., Gorry, J., Gamble, C., & Baker, G.A. (2004). Public knowledge, private grief: A study of public attitudes to epilepsy in the United Kingdom and implications for stigma. *Epilepsia,* 45(11), 1405-1415.

Jacoby, K., & Jacoby, A. (2004). Epilepsy and insurance in the UK: An exploratory survey of the experiences of people with epilepsy. *Epilepsy and Behavior,* 5(6), 884-893.

James, A. (1993). *Childhood Identities: Self and Social Relationships in the Experience of the Child.* Edinburgh: Edinburgh University press.

James, A., & Hockey (2007). *Embodying Health Identities.* Basingstoke: Palgrave Macmillian.

James, A., Jenks, C., & Prout, A. (1998). *Theorizing Childhood.* Cambridge: Blackwell Publishers.

Jenks, C. (1996). *Childhood.* London: Routledge.

Kanemura, H., Sano, F., Ohyama, T., Sugita K., & Aihara, M. (2016). Seizure severity in children with epilepsy is associated with their parents’ perception of stigma. *Epilepsy and Behavior,* 63, 42-45.

Lee, E., Macvarish, J., & Bristow, J. (2010). Risk, health and parenting culture. *Health, Risk and Society*, 12(4), 293-300.

Lee, E., Bristow, J., Faircloth, C., & Macvarish, J. (2014). *Parenting Culture Studies.* Basingstoke: Palgrave Macmillan.

Lupton, D. (1991). Introduction: Risk and sociocultural theory. In D. Lupton (Ed.) *Risk and Sociocultural Theory: New Directions and Perspectives* (pp. 1-11). Cambridge: Cambridge University Press.

Lupton, D. (1999). *Risk*. London: Routledge.

Meyer, A. (2007). The moral rhetoric of childhood. *Childhood*, 14(1), 85:104.

Moffat, C., Dorris, L., Connor, L, & Espie, C.A. (2009). The impact of childhood epilepsy on quality of life: A qualitative investigation using focus group methods to obtain children’s perspectives on living with epilepsy. *Epilepsy and Behavior,* 14(1), 179-189.

Monté, C.P.J.A., Arends, J.B.A.M., Tan, I.Y., Aldenkamp, A.P., Limburg, M., & de Krom, M.C.T.F.M. (2007). Sudden unexpected death in epilepsy patients: Risk factors: A systematic review. *Seizure,* 16(1), 1-7.

Oostrom, K.J., Schouten, A., Kruitwagen, C.L.J.J., Peters, A.C.B., & Jennekens-Schinkel, A. (2001). Parents’ perceptions of adversity introduced by upheaval and uncertainty at the onset of childhood epilepsy. *Epilepsia,* 42(11), 1452-1460.

Prout, A., & James, A. (1997). A new paradigm for the sociology of childhood? Provenance, promise and problems. In A. James, & A. Prout (Eds.) *Constructing and Reconstructing Childhood* (pp. 7-33).London: Falmer Press.

Reis, R. (2001). Epilepsy and self-identity among the Dutch. *Medical Anthropology,* 19(4), 355-382.

Scambler, G. (1989). *Epilepsy*. London: Routledge.

Scambler, G. (1994). Patient perceptions of epilepsy and doctors who manage epilepsy. *Seizure,* 3(4), 287-293.

Scambler, G., & Hopkins, A. (1986). Being epileptic: Coming to terms with stigma. *Sociology of Health and Illness,* 8(1), 26-43.

Scambler, G., & Hopkins, A. (1988). Accommodating epilepsy in families. In R. Anderson, & M. Bury (Eds.) *Living with Chronic Illness: The Experience of Patients and Their Families* (pp. 156-176).London: Unwin Hyman.

Schneider, J., & Conrad, P. (1980). In the closet with illness: Epilepsy, stigma potential and information control. *Social Problems,* 28(1), 32-44.

Schneider, J., & Conrad, P. (1983). *Having Epilepsy: The Experience and Control of Illness.* Philadelphia: Temple University Press.

Sheth, R. (2002). Adolescent issues in epilepsy. *Journal of Child Neurology,* 17, 2S23-2S27.

Shoskat, S., & Fox, N.S. (2012). Forgetting and remembering epilepsy: Collective memory and the experience of illness. *Sociology of Health and Illness,* 34(3), 362-387.

Tonberg, A., Harden, J., McLellan, A., Chin, R.F.M., & Duncan, S. (2015). A qualitative study of the reactions of young adults with epilepsy to SUDEP disclosure, perceptions of risks, views on the timing of disclosure, and behavioural change. *Epilepsy and Behavior,* 42, 98-106.

Webster, M. (2016). *The Experience and Management of Childhood Epilepsy within the Family*. Unpublished PhD thesis, Royal Holloway, University of London.

Webster, M. (2017). Autodriven photo-elicitation interviews: Accessing children’s experiences of epilepsy. *SAGE Research Methods Cases.* DOI: 10.4135/9781473981096

Webster, M. (2019). The cycle of uncertainty: Parents’ experiences of childhood epilepsy. *Sociology of Health and Illness,* 41(2), 205-218.

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(1), 123-136.

Weinbren, H., & Gill, P. (1998). Narratives of childhood epilepsy: Have I got epilepsy or has it got me? In T. Greenhalgn, & B. Hurwitz (Eds.) *Narrative Based Medicine: Dialogue and Discourse in Clinical Practice* (pp. 55-69) London: BMJ Books.

West, P. (1990). The status and validity of accounts obtained at interview: A contrast between two studies of families with a disabled child. *Social Science and Medicine,* 30(11), 1229-1239.

Zartler, U., & Richter, R. (2014). My family through the lens: Photo interviews with children and sensitive aspects of family life. *Children and Society,* 28(1), 42-54.

Zinn, J.O. (2008). Heading into the unknown: Everyday strategies for managing risk and uncertainty. *Health, Risk and Society,* 10(5), 439-450.