**Similarities and differences in the meanings children and their parents attach to epilepsy medications**

**Abstract**

By exploring the meanings children and their parents attached to two household treatments for childhood epilepsy (antiepileptic drugs and emergency medications), this paper broadens our understanding of the way in which children view their medications and how these views can impact on their adherence to treatment. The paper draws on data collected during 2013 and 2014 from 24 families across the UK that had a child with epilepsy aged 3-13 years. In-depth semi-structured interviews were conducted with the parents and 10 children participated in autodriven photo-elicitation interviews. Parents’ and children’s perceptions of medications were compared and contrasted and the findings show that although both parents and children viewed medications as an unpleasant necessity, parents concerns centred on the perceived side effects of medications, whereas the children commented on the process of ingesting medications. Additionally, some of the children had to learn that their medications were a preventative measure, as they originally viewed them as a cure. Furthermore, among the children, it was found that treatment could be seen as either a positive or negative symbol of difference. Lastly, emergency medications were often viewed as a saviour, particularly by parents. Through this analysis, the study shows that the meanings children attached to medications were often linked to the form the medication took and that the way in which children perceived their medications had implications for their adherence; indeed, those who viewed their medications as an unpleasant necessity and those who initially saw their treatment as a cure were most likely to stop taking their medications. Consequently, this paper contributes to the current literature on the meanings individuals attach to treatments by providing the first detailed insight into children’s views on epilepsy medications and by illustrating the similarities and differences in children’s and parents’ perspectives.

**Key Words**

UK; Adherence; Children; Epilepsy; Medications; Parents

**Introduction**

This paper explores the meanings children and their parents attached to two household treatments for childhood epilepsy – antiepileptic drugs (AEDs) and emergency medications (administered in response to prolonged seizure activity).

There is some literature exploring the meanings adults attach to medications (van der Geest & 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 & Lipshitz-Phillips, 1982, 1984; Conrad, 1985; Shoemaker & Ramalho de Oliveira,2008; Webster et al., 2009). However, the meanings children attach to medications have been largely neglected. It is, therefore, intended that this study will begin to address this gap in the literature by detailing the meanings that children with epilepsy attached to their medications. Additionally, comparisons will be drawn between the ways in which children and their parents viewed the different treatments.

There are a variety of meanings 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, pp. 45)

It seems that 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 adults attach to specific prescription medications. For example, when studying the use of psychotropic drugs among those with a range of conditions including anxiety and insomnia, Helman (1981) found that these medications were viewed as 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 lifeline after taking them to treat a range of conditions including depression 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 unnatural (Gabe & Lipshitz-Phillips, 1984; Britten, 1996; Whyte et al., 2002). Indeed, despite increasing use of pharmaceuticals, particularly in the West, the manufactured nature of medications and the fact that they contain chemicals can lead to the perception that they are artificial (Britten, 1996).

Furthermore, being prescribed drugs for chronic conditions in particular has 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 & 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, there is widespread resistance regarding medication use as a result of concerns about that adverse effects pharmaceuticals can have on individual’s health, social activities and relationships (Pound et al., 2005). However, the notion of resistance has been problematised by Chamberlain et al. (2011) who note that it is a complex phenomenon, as the adults in their study would sometimes reject one drug while at the same time accepting another.

The conflicting feelings that individuals experience in relation to the use of pharmaceuticals is partly because, despite side effects and the perception that drugs are unnatural, medications can relieve symptoms. When these symptoms are debilitating it can result in treatments being seen as magic elixirs (Shoemaker & Ramalho de Oliveira, 2008). More generally, 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, drawing on Goffman’s (1963) notion of stigma as ‘undesired differentness’ and his assertion that medications can be stigma symbols, it is probably unsurprising that pharmaceuticals are often prized because they allow treatment to remain personal, as drugs can be administered discretely (van der Geest & Whyte, 1989; van der Geest, 2010).

More specifically 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, little has been written regarding children’s views on medications. One exception is the work of Kärkkäinen et al. (2013) who studied 10 and 11 year olds in Finland and found that they spoke about medication use primarily in relation to the treatment of acute conditions. Furthermore, the children believed that medications would relieve symptoms and speed up the recovery process. 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, there are problems associated with AED treatment; adults have often found the side effects of these medications to be disruptive to their ordinary social conduct (West, 1976; Conrad, 1985; Loring & Meador, 2004). Indeed, drowsiness and impaired concentration have been cited as they most troublesome side effects (Scambler, 1989) due to the implications that these side effects have on individuals’ social interactions (Conrad, 1985). This paper explores how side effects impacted on the meanings children and their parents ascribed to medications for epilepsy. Furthermore, the paper examines how children viewed their treatment more generally and how these views impacted on adherence to their treatment regimens.

**The Study**

The data presented within this paper are drawn from a broader study focusing on the experience and management of childhood epilepsy within the family. During 2013 the research was advertised through seven UK based charities. 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 solely with AEDs and in the other 10 the child was being treated with a combination of medications and the ketogenic diet, which is a treatment for drug-resistant childhood epilepsy (for more information regarding 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. Nine of the children with epilepsy were male, four were female and they ranged in age from five to 13 years.

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, in-depth semi-structured interviews were carried out with one or both parents in 13 of the families. Thirdly, autodriven photo-elicitation interviews were conducted with the children with epilepsy (10 in total). All of these interviews were conducted face-to-face and with families living in the UK.

It was hoped that the same procedure could be followed in families using the ketogenic diet, but because it was not possible to recruit children with epilepsy in these families, one in-depth semi-structured interview was conducted in each family (10 in total). Six of these 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; those who were interviewed face-to-face were all from mainland UK, those who were interviewed over the phone were from non-mainland UK and the Skype and emails interviews were with parents from Eastern Europe and Western Europe (all the interviews were conducted in English).

All of the interviews that involved children included a task in order to engage the children and provide a stimulus for talk. During the group interviews family members made plans of anything they did on a typical weekday and weekend day. The children were then given a single-use camera each and were asked to take photos on four topics, one of which was ‘what epilepsy means to me’. During the children’s interviews, they were asked to talk about their photos and as they did the researcher asked questions about the topics that the children introduced. The researcher also used an interview schedule to ensure that similar topics were covered in each interview. For example, all children were asked about their medications, their experience of seizures and what impact they felt their epilepsy had had on their life.

One difficulty with interviewing the children was 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. Equally, the children sometimes used descriptive phrases that the researcher was unable to identify with. The researcher consequently learnt to be continuously reflexive regarding her use of language. (For more detailed reflections regarding the use of photo-elicitation with children see Webster, 2017).

All interviews were audio-recorded and transcribed *verbatim.* The analysis 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), 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. 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 & Strauss, 1999; Charmaz, 2006). Codes were developed from the meanings in the participants’ speech and the researcher wrote memos describing her thoughts on the developed categories and how they related to each other. Data collection continued until categories became ‘saturated’ and no new theoretical insights were gleaned from subsequent data (Glaser & Strauss, 1999; 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 data collection. All participants gave informed consent and participants and their family members are referred to using pseudonyms. Where extracts from the children’s interviews are used their age is given in brackets.

**Findings**

The findings presented below highlight similarities and differences in the ways in which children and their parents perceived medications for childhood epilepsy. To begin, the view that AEDs were a preventative measure is examined. Next, the perspective that medications were an unpleasant necessity is outlined. Following on from this, the way in which the children saw medications as positive and negative symbols of difference is discussed. Lastly, emergency medications in particular were seen as a saviour and this point of view will be explained in the final subsection.

*Treatment 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.

Similarly to the parents, children also principally viewed their daily medications as a way of preventing their seizures. 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 decided to stop 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’.

Although Ross thought his medication had cured his epilepsy, he went on to have another seizure and admitted to his mum that he had been putting his medicine down the sink. When parents gave children responsibility for administering their own medication, which was usually around 10 or 11 years of age, this responsibility was often removed when parents found that children had stopped taking their AEDs. Therefore, despite children’s perceptions influencing their adherence to treatment, there were nevertheless limits on this as parents often had the ultimate control.

Similarly to Ross’ perception of his medication, Zara explained 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.

In this instance, Zara was in control of Isaac’s medication and he, therefore, did not discontinue use despite his views. However, these examples 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 children often associate medications with recovery (Kärkkäinen et al., 2013), which may help to explain why these two boys seemed to initially believe that their medications were cures. Indeed, when Ross and Isaac’s 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.

*Treatment 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 aligns with the ambivalence described by Gabe and Lipshitz-Phillips (1982, 1984) in relation to their work on benzodiazepines. However, rather than an ‘evil necessity’ 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 treatment was currently having, 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*.*, whonote that it is common for medications taken for chronic illnesses to be positioned as ‘necessary, but taken with reluctance’ (2011, pp. 303). However, this example shows that reluctance can relate to a family member’s medication use, rather than an individual’s own consumption.

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.

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 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 bi-polar 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.

It has previously been 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 & Ramalho de Oliveira, 2008; Dew et al., 2015) and that people tend to attach negative meanings to drugs if they view them to be too ‘strong’ or aggressive (van der Geest, 2010). Here Heather’s negative association with this particular type of medication seems to have been influenced by the fact that she found out that it was also used to treat mental illness. Heather, therefore, had concerns regarding the potential mind-altering consequences of this drug.

Overall, despite negative views of the child’s AEDs, all parents continued treatment as they felt the preventative aspect of continued medication use outweighed the perceived 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 & 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 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 current 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 and began hiding them in her bedroom 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. Furthermore, although parents and children reached the same conclusion regarding this meaning, they had very different priorities – the children were primarily concerned with the process of ingesting medications, whereas the parents focused on current side effects of medication use. A meaning that was more commonly applied by the children is discussed below.

*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; 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 is likely to be 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 medications negatively was gleaned from other family members, particularly parents. For instance, 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 and also thought that he felt his medications were stigma symbols (Goffman, 1963) that would draw attention to his epilepsy if he were to take them publicly.

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 (a brand of over-the-counter children’s liquid paracetamol in the UK) 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, when Tom’s response is placed in the context of his interview, where he answered questions directly about epilepsy by saying ‘don’t know’ and frequently changed the subject, 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 because of its widespread use amongst children, in contrast to AEDs. Although tom did not explicitly say whether he viewed his medication positively or negatively, his interview data suggests that he did not want others to know about his condition and this is why he did not want to speak about this topic to the researcher.

Similarly to Tom’s preference for taking his medications in private, some families expressed a preference for particular forms of medication for comparable reasons. 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.

In contrast to the children who saw their AEDs as a negative symbol of difference, two children felt their AEDs differentiated them 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. 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!

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 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.

*Treatment as a Saviour*

Both forms of household treatment were, at times, 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. 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 [Sudden Unexpected Death in Epilepsy] 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, for instance, he said ‘sometimes I think, you know ‘I could die from it’’. The extract above 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.

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.

**Discussion**

This paper has explored the meanings children and their parents attached to two household treatments for childhood epilepsy – AEDs and emergency medications. In doing so, this paper provides the first insight into the meanings that children attach to epilepsy medications. It has been shown that children’s and parents’ perceptions of medications often varied, and when they did attach the same meaning this could be the result of different considerations. Furthermore, it has been illustrated that the way in which children view their medications can have implications for their adherence to treatment.

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. 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.

It has previously been argued that children’s experiences are not synonymous with those of their parents (Christensen, 1998) and this was particularly highlighted here in relation to children’s experiences of epilepsy treatments. Indeed, although the children also saw their medications as an unpleasant necessity, the negative aspect of medication use that influenced their view was the process of ingesting medications, rather than any current side effects that the medications caused. Indeed, the taste of liquid medications was unpleasant for many of the children and some had also experienced difficulties swallowing tablets. It was found that when children viewed their medications as an unpleasant necessity, if they took responsibility for administering their own medication, they sometimes chose to stop taking it. It is, therefore, important for consultants and parents to be aware of the way in which children view their medications so that these issues can be resolved in order to minimise the possibility of children abruptly stopping their treatment.

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, as we saw in relation to Ross and Isaac. This view had implications for children’s adherence to medication regimes; those who originally saw their medications as a cure were likely to think that they no longer needed their medications once their symptoms were being controlled. It is argued that the meanings some children associated with medications changed over the course of treatment to incorporate the chronic nature of the condition. Indeed, over time children came to see medication as a preventative measure rather than a cure. Knowing that children my not always understand the need for continued medication use for chronic conditions could inform the way in which chronic illnesses and treatments are communicated to them in the first instance.

An additional finding is that, in contrast to their parents, it was mainly the children that saw medications as a symbol of difference. Some children saw treatment as a symbol of difference in a negative sense, indicating that, as Goffman (1963) has argued, medications can be seen as stigma symbols. Moreover, 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.

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. Therefore, as it was principally the form the medication took that resulted in children attaching negative as well as positive meanings to their treatment regimens, 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. In contrast to this, parents primarily focused on the effect that they felt medications were currently having.

An additional positive meaning that was attached to epilepsy medications was most commonly applied by parents and related to the use of emergency medications. Indeed, in nine of the 11 families where emergency medication had been prescribed, parents held overwhelmingly positive views of this treatment as it was seen as a way of saving the child’s life. This, therefore, reinforces Webster et al.’s (2009) argument that when a medication is effective and symptoms are seen as debilitating (in this case symptoms were potentially life threatening/altering), treatment was viewed positively and resulted in feelings of safety.

This paper has also contributed to the literature surrounding experiences of living with epilepsy. Research to date has tended to focus on adults’ experiences (Schneider & Conrad, 1983; Conrad, 1985; Scambler, 1989). However, this study has illustrated that children’s experiences may differ to those of adults living with the same condition. For instance, adults have been found to focus on the side effects of medications (Conrad, 1985; Scambler, 1989), whereas the children in this piece of research rarely spoke about side effects.

Overall, this paper has shown that in order to understand children’s experiences of living with a chronic condition it is important to explore the meanings that children attach to medications and to not assume that children’s and parents’ views align. Indeed, it was primarily the parents that saw mediations as a saviour and only children that felt medications were a symbol of difference; additionally, when parents and children saw medications as an unpleasant necessity this was the result of different considerations. Importantly, it has been illustrated that children’s perceptions of their medications can impact on their adherence; for instance, when children viewed medications as an unpleasant necessity or as a cure rather than a preventative measure they were more likely to stop taking their medications. Furthermore, children feeling their medications were negative symbols of difference impacted on the situations in which they were comfortable taking their medications. Consequently, it is necessary to explore the ways in which children view their medications in order to understand their adherence to treatment regimens, as their perspectives are likely to differ to the views of adults.

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