



A qualitative study of the barriers and enablers to antiseizure medication adherence in children with epilepsy

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ABSTRACT

Purpose: The aim of this study is to explore the barriers and enablers to antiseizure medication (ASM) adherence in children with epilepsy and their carers to inform the development of a tailored intervention.

Methods: A qualitative study was conducted between November 2025 and February 2026 using semi-structured interviews among children with epilepsy aged 5 to 12 years and their carers. Participants were recruited using purposive recruitment sampling through epilepsy charities. Interviews were conducted on Microsoft Teams lasting 35 to 84 min. Data were analysed using reflexive thematic analysis in NVivo 14, with attention to both child and carer perspectives.

Results: Ten interviews were conducted with seventeen participants; three with carers only and seven with children and their carers. Four themes were generated from the analysis which were; medicine cognition and emotional experience, organisation and practical management of medicine, medication formulation and administration practice and the role of social and professional support. While children primarily voiced concerns about medication formulation, particularly taste, parents focused more on side effects and the importance of treatment routines. Some parents of children with learning disability additionally expressed concerns about the colour of their medication.

Conclusion: Our findings highlight the potential determinants to antiseizure medication adherence in children with epilepsy and their carers/parents. Factors influencing adherence included child, parent and system level influences. We recommend that Healthcare professionals (HCPs) should proactively identify and address formulation-related challenges to support adherence and prioritise clear communication about treatment expectations.

1. Introduction

Epilepsy is a common neurological condition affecting approximately 1% of children globally [1]. The World Health Organisation (2024) reports that anti-seizure medicines (ASMs) are effective in controlling seizures in approximately 7 out of 10 individuals [2]. Despite the proven effectiveness of ASMs, non-adherence to ASMs remains a significant challenge, with estimates ranging from 26% to 79% [3]. This suboptimal adherence is associated with serious consequences such as poor seizure control, increased risk of mortality, prolonged

hospitalisation, increased healthcare costs and reduced quality of life [4–6].

Medication adherence was conceptualised according to the ABC taxonomy as the extent to which medicine taking behaviour corresponds with the agreed recommendations of the healthcare professional, including treatment initiation (when the first prescribed dose is taken), implementation (taking medicine as prescribed from initiation until last dose) and persistence (continuing treatment from initiation until discontinuation) [7].

In children with epilepsy (CWE), adherence is particularly complex

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and influenced by a range of child, caregiver and system level factors [8]. Evidence suggests that barriers to ASM adherence vary by age group, with younger children (0–12 years) experiencing challenges related to medicine formulation, while older children (13–18 years) are more likely to report concerns about stigma associated with taking ASMs [8]. This highlights the need for age-specific studies on adherence behaviours.

Our prior meta-ethnography synthesised qualitative evidence on barriers and enablers to ASM adherence in CWE and highlighted areas where evidence remained limited [8]. Although previous studies identified several factors influencing adherence, it remained unclear whether some determinants had been underexplored due to limitations within the existing literature. Therefore, further qualitative exploration was required to gain a more comprehensive understanding of factors influencing adherence from the perspectives of CWE and their families within the UK.

Previous studies conducted to explore the experiences of CWE have

largely excluded those with intellectual disabilities (learning disability in UK terminology) and other neurodevelopmental conditions or learning needs [9–11]. It is estimated that about 60.3% of studies have excluded individuals with learning disabilities from research [12]. A systematic review estimated that 22.2% of people with learning disabilities have epilepsy, highlighting the importance of ensuring that this population is represented in epilepsy related research [13].

Therefore, this study aims to explore the barriers and enablers to ASM adherence in younger children (5–12 years) with epilepsy and their families. Using a qualitative approach, the study aims to develop an in-depth understanding of these experiences and extend findings from our previous studies, to inform the development of a tailored intervention.

Table 1

Interview guide.

TOPIC GUIDE
<ul style="list-style-type: none"> • Welcome and introduction • Seek consent to continue and to audio record the interview • House keeping <p>Task Draw a picture which shows how you feel about taking your medicine. (Children participating in this study were asked to draw this in advance and sent before interview.)</p> <p>Ice break</p> <p>Tell me a bit about you and what you are interested in? Questions</p> <p>1. Children: You had a chance to draw a picture about how you feel about taking your medicine. Can you tell me about your drawing and why you have drawn it this way?</p> <p>♦ Prompts:</p> <ul style="list-style-type: none"> • How does your medicine make you feel taking it? (taste, texture, size) • Which type of your medicine do you like best? (liquid, tablets, chewable, dissolvable)? <p>2. Parent: Can you tell me what a typical day of managing your child's epilepsy medicine looks like for you?</p> <p>Prompts:</p> <ul style="list-style-type: none"> • How does the medicine routine look like from morning to bedtime? • Who usually helps with giving the medicine? <p>3. Children: Can you tell me why you take your medicine?</p> <p>Parent: Can you tell me why you give the medicine to your child?</p> <p>♦ Prompts:</p> <ul style="list-style-type: none"> • Why it is good to take the medicine? • Where do you get your information about the medicine from? • In what ways do you think your medicine helps or does not help you? <p>4. Parents: How do you find giving your child their epilepsy medicine regularly? ♦ Prompts:</p> <ul style="list-style-type: none"> • Do you feel confident managing the medicine routine every day? • Is anything still hard for you when giving medicine? • Have you ever missed giving a dose? What helped you get back on track? <p>5. Children: What can your parents do to help you take your medicine as you are meant to take it.</p> <p>Parents: What do you do to help your child feel more motivated to take their medicine?</p> <p>♦ Prompts:</p> <ul style="list-style-type: none"> • How did that make you feel? • What kind of reward or praise helped? • Did it make it easier to take your medicine the next time? <p>6. Children: If you could design the perfect medicine for yourself, what would it be like?</p> <p>Parent: If you could design the perfect medicine for your child, what would it be like?</p> <p>♦ Prompts:</p> <ul style="list-style-type: none"> • How should it taste like? • How would you want to take it (tablet, liquid, dissolvable, chewable) • What would make it easier for children like you to take medicine on time? <p>This is your opportunity to bring up anything about the medicine that we haven't already discussed, that you think make it challenging to take them, or help your child take them. Is there anything else you think I should know? Thank you so much for talking with me today. I will go away to speak to more children and parents. I will also provide feedback when we are done with all the interviews.</p>

2. Methods

2.1. Study design

This study was underpinned by a subtle realist epistemological position. This study followed the Consolidated Criteria for Reporting on Qualitative Research (COREQ). We used online semi-structured interviews conducted with parents and their CWE.

We selected interviews due to the potentially sensitive nature of discussing health-related experiences and supported open and honest communication. In addition, interviews helped to maintain the confidentiality and privacy of both children and their parents [14].

The interview guide was informed by findings from a prior systematic review conducted by the research team, in which barriers and enablers to ASM adherence were synthesised and mapped to the TDF [15]. Whilst the researchers initially intended to design the interview guide to specifically probe TDF domains that had not been adequately captured in previous research (Behavioural regulation, Goals, Social/professional role and identity, Beliefs about capabilities, Skills and Reinforcement) [16]. This approach was not adopted to avoid constraining participants' accounts within predetermined domains. Instead, the previous TDF-informed work informed the researchers' thinking during the development of the interview guide. This approach allowed participants to describe their experiences openly and to generate novel insights into factors influencing paediatric ASM adherence.

To facilitate participation among younger children, a creative activity was incorporated in which children were asked to draw a picture representing how they feel about their ASM [17]. Interview topics included parents' experiences of managing their child's ASM daily, children's understanding of why they take medicine and perceptions of what "ideal medicine would look like". (See Table 1 for full interview guide).

Ethical approval for the study was granted by the University of Leicester Research Ethics committee (Project ID: 3951).

2.2. Patient and public involvement

The PPI team comprising two parents of CWE and two adults with epilepsy and a CWE contributed throughout the study. None of the PPI members participated in the research interviews.

The PPI members reviewed and refined the participant information sheet, privacy notice, recruitment flyer, consent and assent forms and interview guide, study design to improve their clarity, acceptability and relevance to families affected by epilepsy. For example, following a mock focus group, PPI group raised concerns about confidentiality, which led to the initially planned focus group design being changed to individual family interviews. They also suggested replacing "pharmacists" with the more child-friendly term "chemists" in the assent form.

Following completion of the initial analysis by the research team, PPI members reviewed anonymised thematic summaries and illustrative quotations. Their feedback helped determine whether the themes reflected their experiences, improved the interpretation of the findings and ensured the language used was understandable and meaningful to patients and families. For example, they highlighted the importance of medicine availability at community pharmacies and limited consultation time with healthcare professionals, prompting further consideration of these issues when interpreting the findings. Formal coding or theme generation was the responsibility of the research team. The PPI members provided feedback on dissemination plans and the communication of study to patient communities. The PPI involvement was reported with reference to the Guidance for Reporting Involvement of Patients and the Public 2 (GRIPP2) reporting guidance [18].

2.3. Recruitment

Participants were recruited purposively through Epilepsy Action and

Young Epilepsy to obtain a diverse sample of CWE and their parents/carers across a range of age, gender, epilepsy types and locations within the UK. Eligible participants were recruited consecutively until sufficient information power was achieved. Whilst efforts were made to reach a diverse population, no formal sampling matrix was maintained.

Information power is a pragmatic model in assessing the sample size in a qualitative study [19]. Information power was considered in relation to the specificity of the study aim, the specificity of the sample, the richness of the interview data and analytical strategy [19]. The study was theoretically sensitised by prior TDF-informed work [15]. The study had a focused aim of understanding the experiences and factors influencing ASM adherence among children with epilepsy and their parents/carers. Although the children were clinically heterogeneous, participants represented a specific sample with the shared experience of managing and taking ASMs for epilepsy. The study was theoretically sensitised by previous TDF-informed work, although the TDF was not used to structure the interview questions. The semi-structured interviews and follow-up prompts generated rich and detailed accounts from children and parents/carers. Despite the analysis involving cross case analysis, reflexive thematic analysis enabled an in-depth, interpretative examination of patterns of shared meaning across participants' accounts.

Sample adequacy was considered iteratively during data collection and analysis. The research team discussed the richness, relevance and diversity of the information generated by the interviews in relation to the information power model as data collection and analysis progressed. Following ten family interviews (ten parents and seven children), the research team judged that the dataset provided sufficient information power to address the study aim and that further interviews were unlikely to substantially extend the insights relevant to the research question. Recruitment was therefore concluded.

Research managers within these charities, acting as gatekeepers, distributed the recruitment flyer across their networks. The inclusion and exclusion criteria were shared with the research managers and dissemination was targeted to relevant groups to minimise expressions of interest from individuals who did not meet the study eligibility criteria.

The inclusion criteria were:

- children diagnosed with epilepsy for at least six months.
- Parent/carer of child diagnosed with epilepsy for at least six months.
- Aged 5–12 years.
- Fluent in English.
- Live in the UK.
- Currently taking ASM.
- Access to digital device for online participation.

Following consent, participants completed a Microsoft online form to provide demographic information. This information was used to confirm eligibility against the inclusion criteria. In this study, information regarding learning disability was obtained through parent self-report using the questionnaire. Parents were asked whether their child had a learning disability, the term commonly used in UK healthcare. See Supplementary file 1 containing the demographic questionnaire.

2.4. Procedure

Interviews were then convened based on agreed time and date between the parent and EK. For interviews involving both a parent and a child, parents were contacted in advance to discuss the child's individual needs and preferences, including whether the child would prefer being interviewed independently or together with their parent.

Three interviews were conducted with parents only: two because the children were non-verbal and one because the child was unwell at the time of the interview. All seven children who participated in the interviews indicated that they preferred their parent to be present during

the interview, hence no child was interviewed independently. Interviews were semi-structured with open-ended questions and prompts to facilitate participant led and in-depth discussions. All interviews were conducted by EK (male, PhD student with experience of conducting interviews).

An interview guide was designed to understand experiences of children and their parents in taking their epilepsy medicine and explore the missing domains from our previous study. An illustration of the questions and prompts is provided in Table 1. See Table 1 below for interview guide.

For younger children, drawings created by them prior to the interview were included into the discussion to support engagement and expression of their experiences. The drawings themselves were not analysed as data, rather, the children's verbal explanation informed the analysis. Drawings were used only as engagement tool and was not systematically analysed. The interviewer used age-appropriate language, simplified or rephrased questions where necessary example using words such as "medicine" instead of "medication", and incorporated prompts to encourage children to expand on their experiences while maintaining the intended meaning of each question. Throughout the interview, children were reminded that they could choose not to answer any question, take a break or stop the interview at any time without providing a reason. See supplementary data file 4 for child assent sheet.

At the end of each interview, participants were reminded of available support networks should any issue arise from discussing their ASM administration challenges.

2.5. Data analysis

This study adopted an experiential approach, focusing on understanding participants' accounts and experiences of ASMs from their own perspectives. Interviews were digitally audio-recorded and transcribed using Microsoft Teams, with transcript subsequently checked and corrected by EK.

This study was theoretically sensitised by our prior work using the TDF [15], which informed our thinking during the development of the interview guide. Coding and theme development for the analysis were primarily inductive, whereby themes were developed directly from the data. Data were analysed using reflexive thematic analysis, following the six phase framework described by Braun and Clarke [20]. These phases included: 1. Familiarisation with the data, 2. Coding, 3. Generating initial themes, 4. Review and development of themes, 5. Refining, defining and naming of themes and 6. Writing up.

All transcripts were transferred to NVivo 14 Software to help with data management, coding and thematic development. Data were coded to identify patterns relating to barriers and enablers to ASM adherence, which informed the development and interpretation of themes across the transcripts by EK. The data analysis was conducted concurrently with data collection, with each interview transcribed and initially coded before subsequent interviews, enabling continuous engagement with the data throughout the process. Coding was undertaken primarily at the semantic level, while interpretation was informed by participants' experiences and context. Codes were refined, and previously coded transcripts were revisited as new insights emerged. Related codes were grouped into preliminary themes representing broader patterns of shared meaning across participants' experiences. Themes were developed through iterative process of reading transcripts, reviewing codes and refining patterns across transcripts. Patterns of shared meaning essential to understanding the barriers and enablers to ASM adherence were developed into themes, provided they addressed the study aim and were organised around a central organising concept. Throughout the analysis, regular discussions were held with the supervisory team. Supervisors independently reviewed selected interview transcripts and thematic summaries, and discussions were used to challenge interpretations, explore alternative explanations, refine the developing themes and support reflexive dialogue.

Although interviews were conducted at the family level, parents' and children's accounts were analysed as individual perspectives. Where child and parent described same experience, each account was retained and coded independently to preserve both perspectives. During data interpretation, overlapping accounts were considered complementary evidence for the same concept rather than duplicated findings. Where parent and child expressed differing views, both perspectives were retained and analysed without attempting to reconcile them, as these differences were considered meaningful and provided insight into the barriers and enablers influencing ASM adherence. This study adopted an experiential approach, focusing on understanding participants' accounts and experiences of ASMs from their own perspectives. Initial coding and theme development were undertaken by EK. These interpretations were discussed with DW, SS and CS as a form of reflexive dialogue, providing opportunities to challenge assumptions, consider alternative interpretations and deepen engagement with the data resulting in the development of the final themes. In addition to the inductive analysis reported here, the same transcripts underwent a separate deductive analysis, in which data were mapped to the TDF domains to identify behavioural determinants to help with intervention development. The TDF analysis is reported separately.

2.6. Reflexivity

Interviews were conducted by EK, a registered nurse and second year PhD student who had undertaken training in qualitative research. EK's clinical nursing background and previous research on medication adherence provided prior knowledge and assumptions about medicine taking behaviours, including an awareness of the importance of adherence and the potential consequences of non-adherence. These perspectives were acknowledged as part of the interpretative process.

Before this study, EK and DW had collaborated with Epilepsy Action (UK based epilepsy charity) on an unrelated project involving the analysis of existing dataset and preparation of findings for publication. However, they had no prior relationship with any study participants and was not involved in their clinical care. At the start of each interview, EK introduced himself as a research student with no involvement in participants' clinical care.

Parents were contacted prior to interview to discuss any communication or support needs of their child and to agree on the preferred interview format. Children were encouraged to answer questions first, parents were asked not to interrupt, and ice-breaker questions were used to reduced power imbalances and promote open discussion.

The wider research team brought diverse disciplinary, methodological and clinical perspectives. DW is a pharmacist with expertise in medicines use, SS is a behavioural scientist with expertise in qualitative research, CS is a Speech and Language therapy with expertise in qualitative research, CL is a neurologist with clinical expertise in epilepsy. These perspectives informed aspects of the study design, for example, CL advised on the inclusion of children with learning difficulties to ensure that their experiences were represented in the study. EK, DW, CL and AS had also been involved in epilepsy related research and professional activities prior to this study, providing familiarity with the clinical and medication related context of epilepsy. These prior experiences provided relevant contextual knowledge but may also have shaped the team's assumptions and interpretations of participants' accounts.

Reflexive notes were maintained throughout data collection and analysis and discussed during regular supervisory meetings. The different disciplinary perspectives within the team provided opportunities to challenge initial interpretations, consider alternative explanations, refine and rename themes and develop deeper interpretations of the data. For example, "network of supporting shaping medication adherence" was changed to "the role of social and professional support". These discussions functioned as reflexive dialogue to broaden and deepen the lead researcher's interpretation. The research team recognised the potential for a pro adherence orientation and designed the

interview guide to explore both barriers and enablers, encouraging participants to share positive and negative experiences.

This study is funded by Desitin Pharma Ltd. AS represented the study funder. The funder had no role in the study design, recruitment, data collection, analysis, interpretation, manuscript preparation or publication decisions and was only updated monthly of the progress of the study. Also, DW receives consultancy income from pharmaceutical companies including Desitin Pharma Ltd.

3. Results

Nineteen families expressed interest in this study, one was excluded because the child was over 12 years and seven did not return or complete consent forms. One family was not recruited because data collection had concluded. A total of 10 families (ten parents and seven children) participated in the study from November 2025 to February 2026. Parent-only interviews had a mean duration of 41 min (range: 33–51 min), while joint parent-child interviews had a mean duration of 58 min (range: 36–85 min). Table 2 shows the demographic data of the parents and children who participated in the study. Demographic variables are presented in categories rather than as individual characteristics to minimise the risk of participant identification.

After the analysis, 4 themes and 14 sub themes were generated from the data. Fig. 1 illustrates the themes and sub themes identified in this study.

3.1. Medicine cognition and emotional experience

This theme explores how parents and children reported the trust or were uncertainty regarding the effectiveness and safety of ASMs and how these perceptions shaped medicine-taking experiences.

3.1.1. Trust in effectiveness and safety of medicine

Across the interviews, the perceived role of medicine in maintaining

safety was identified as an enabler of adherence. Both children and parents described ASMs as important for preventing seizures and maintaining safety. Parents emphasised this message explicitly to their children to help children understand the reason for taking their medicine.

I take my medicine to stop me to stop me from having seizures. (Child 4)

However, in families where children experienced ongoing or breakthrough seizures despite medicines, uncertainty about the effectiveness of the ASM was seen as a barrier, as parents described the difficulty of sustaining the narrative that medicine prevents seizures when seizures continued to occur.

3.2. Adverse effects of the medicine

Alongside beliefs about effectiveness, side effects also influenced adherence. Although seizure control was acknowledged as essential, side effects both experienced and anticipated influenced parents giving ASM to their children. Parents described side effects, particularly fatigue, mood changes, and cognitive concerns. Parents also reported the burden of managing additional medicines to counteract side effects.

I'd heard about side effects of medicine, so I was terrified about. What if it makes her sleepy and at that point, she was only 18 months old and I didn't know she had a cognitive issue, so I was like, oh, no, what if it impacts on her learning? And as it is, it probably has impacted on her learning, but also so have her seizures (Parent 1)

3.3. Organisation and practical management of medicine

This theme explores how the organisation and day to day management of ASMs, including routines, medicine availability, brand consistency and strategies to prevent lapses, influenced medicine adherence.

Table 2
Demographic data of research participants.

ID	Relationship to child	Geographical region	Child's ethnicity	Child's gender	Child's age	Child's epilepsy type	No of years with epilepsy	Learning disability	Medication prescribed	Formulation type
Parent 1***	Mother	England	White-British	Female	11–12	DEE*	>5 years	Yes	≥3 ASMs + ketogenic diet	Mixed**
Parent 2***	Mother	England	White-British	Female	11–12	Genetic epilepsy	>5 years	Yes	1 ASM + Ketogenic Diet	Mixed**
Parent 3, child 1	Father	England	White-British	Female	8–10	Genetic Epilepsy	>5 years	No	1 ASM	Liquid
Parent 4, Child 2	Mother	England	White-British	Female	5–7	Focal epilepsy	<3 years	No	≥3 ASMs	Liquid
Parent 5, Child 3	Mother	England	White-Any other white	Female	11–12	Focal Epilepsy	<3 years	No	1 ASM	Solid
Parent 6, Child 4	Mother	England	White-British	Male	11–12	Generalised epilepsy	>5 years	Yes	2 ASMs	Solid
Parent 7, child 5	Mother	Northern Ireland	White-British	Female	8–10	Focal epilepsy	3–5 years	No	2 ASMs	Mixed**
Parent 8, child 6	Mother	England	White-British	Female	8–10	DEE	>5 years	Yes	2 ASMs	Mixed**
Parent 9****	Mother	England	White-British	Male	8–10	Generalised epilepsy	3–5 years	No	1 ASM + Emergency medicine	Liquid
Parent 10, Child 7	Mother	England		Female	8–10	Focal Epilepsy	>5 years	Yes	2 ASMs	Solid

*DEE- Developmental and epileptic encephalopathy.

**Mixed- combination of liquid and solid formulation.

***Only parents participated in the interview as children were non-verbal.

****Only parent participated in the interview as child was unwell.

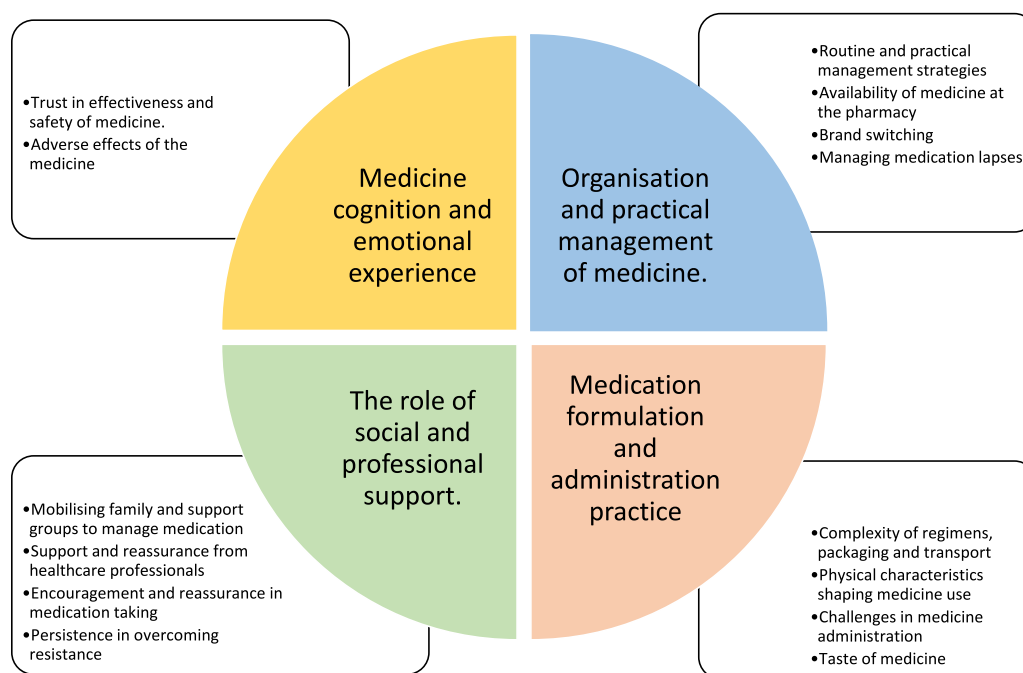


Fig. 1. Themes and subthemes that emerged from the interviews.

3.3.1. Routine and practical management strategies

Building routine acted as an enabler. Parents and children reported that embedding ASM into fixed times and structured daily activities reduced resistance and made medicine taking a routine which improved adherence. For some children, particularly those reported having learning disability, routine provided stability and reduced anxiety.

“It seems kind of like in the morning when he kind of gets dressed, medicine is kind of with his breakfast, it’s kind of rhythm and routine. We’re kind of saying breakfast, let’s do your medicine at the same time. That’s the only way really we’re kind of tracking it” (Parent 9).

3.3.2. Availability of medicine at the pharmacy

Beyond household routines, external factors such as pharmaceutical supply influenced adherence. Medicine availability, stocking practices, national shortages, and cost considerations were considered a barrier to treatment continuity.

While some parents reported stable access (obtain medicine) to specific brands, many described recurring challenges in obtaining the correct medicine from the pharmacy. As a result, parents described needing to request prescriptions in advance to be able to get the medicine on time.

“we struggle to get hold of the brand so we were ringing round, I think we rang seventeen pharmacies to be able to get hold of that” (Parent 4).

3.3.3. Brand switching

Consistently, medicine supply issues often resulted in changes to brand or formulation. Parents described repeated instances where pharmacies dispensed alternative brands or formulations without prior discussion.

“We’ve had the clobazam technically doesn’t have to be the same brand, but we have had difficulties with new brands causing more seizures” (Parent 4).

Several parents perceived that changes in medication brand or formulation created uncertainty and, in some cases, were associated with poor seizure control.

3.3.4. Managing medication lapses

Despite these supply issues, forgetfulness and confusion were also identified as barriers, yet families actively mitigated these risks using reminder systems and written records.

Families reported that lapses occur during busy days. Parents and children described moments of forgetfulness, confusion, delayed doses or near miss errors (given medicine later than prescribed). Highlighting the cognitive demands of managing long-term ASM use. Several parents described morning routines, school transitions, holidays and competing responsibilities as situations in which missed or delayed doses were more likely to occur.

3.4. Medication formulation and administration practice

This theme describes how physical and formulation-related characteristics of ASM influenced adherence by shaping medicine acceptability, administration, and everyday medicine management.

3.4.1. Taste of the medicine

Taste functioned as a key determinant perceived to influence adherence. Palatable taste was identified as an enabler and normalised medicine taking.

Children frequently expressed strong preferences for sweet or fruit-flavoured formulations, particularly strawberry. Conversely, unpalatable taste hindered adherence. Some children reported dislike of the taste of their medicine and in some cases, requested to switch formulations.

“I don’t like it because the banana one doesn’t taste very nice” (Child 2)

To mitigate unpleasant taste, parents masked or neutralised the flavour of the medicine. These included mixing medicine with Nutella. Also, parents expressed that they administered unpleasant medicines quickly before more palatable ones; or providing something sweet immediately afterwards to remove the lingering taste.

“We cover it (medicine) in Nutella, so he has his medicine on a slice of bread with Nutella and he always has so it’s kind of masked the taste” (Parent 6).

These strategies were described by parents as practical approaches to

improve medicine administration.

3.4.2. Challenges in medicine administration

In addition to taste, families described practical barriers associated with how medicines were administered. Equipment design, formulation properties and dietary compatibility were perceived to influence medicine adherence. For instance, parents reported that inadequate dosing equipment created challenges in accurate administration.

“Epilim comes with a cup, so it doesn't even come with the syringe, we can't dose 8 mls when it's a 5 mls, 10 mls line. So, you can't dose it. And then the Stiripentol just doesn't come with anything” (Parent 8).

Parents also reported that in situations where liquid medicine was partially expelled from the mouth of the child, they were required to make real time judgements about whether to re administer and how much, balancing the risk of underdosing against overdosing.

Dietary restrictions added further complexity. Some parents of children following a ketogenic diet described crushing tablets or mixing powders with food because they perceived liquid formulations to be unsuitable.

3.4.3. Physical characteristics shaping medicine use

Beyond administration challenges, medicine formulation and physical properties played a significant role influencing children's experiences and adherence practices.

While some parents expressed that liquid formulations were easier to administer in younger children, some children preferred tablets, especially those who dislike the taste of the liquid medicine. Smaller tablet size was seen as more acceptable. Also, tablets were perceived as beneficial for dental health, with one parent noting improved tooth appearance in their child after stopping liquid formulations.

Again, dispersible tablets were viewed positively, as they could be crushed, dissolved, or swallowed whole depending on the child's developmental stage.

I don't know why anyone would take not dispersible ones. If you can just pop them and swallow them and you said they taste really sweet (Parent 5).

Parents, however, expressed that the colour of liquid medicines posed practical difficulties as this stained the teeth of their children. Two parents perceived that brightly coloured liquid formulations were associated with behavioural changes in their children, who were reported to have learning disability.

“Epilim is also red and stains everything. It doesn't matter what you do, it gets everywhere” (Parent 8)

3.4.4. Complexity of regimens, packaging and transport

Alongside the formulation challenges, the overall complexity, dosing, packaging and storage requirements, played a significant role in shaping adherence. Parents reported that simplified regimens, such as once-or twice daily dosing and prolonged-release formulations, were more compatible with family routines and easier to manage. Parents also expressed a preference for child-friendly packaging that facilitated easier administration.

Despite these enablers, multiple barriers related to medicine complexity were reported. Parents further reported practical challenges associated with transporting particularly liquid formulations in glass bottles. Increasing doses were described as particularly challenging, especially with liquid formulations, as the volume became gradually harder for children to tolerate.

“we had to move to tablets because (the) child was really struggling with the liquid medicine, particularly when, as she was growing, it became quite a lot to take, and it could take us up to 20 min to half hour. (...)” (Parent 10)

3.5. The role of social and professional support

This theme describes how social and professional support shaped medicine adherence through encouragement, reassurance, information sharing, and practical support from families, peers, charities and healthcare professionals.

3.5.1. Encouragement and reassurance in medicine taking

Encouragement and reassurance operated as key enablers that supported consistent medicine taking among these children. Parents expressed that verbally praising children helped to improve adherence. Positive reinforcement strategies were employed, including reward charts and tangible rewards. For some families, food-based incentives were used, particularly when medicines were unpleasant in taste.

Encouragement extended beyond rewards. Parents described sitting with their child, offering reassurance, coaxing and gently and remaining present until the medicine was taken.

“we used to do medicines first, then milk. You know, that was her. The milk was her reward really for having her medicines” (Parent 2).

However, reluctance and low mood acted as barriers to adherence. Parent expressed that, on days when children experienced low mood or fatigue, resistance to medicine increased, requiring additional encouragement and support from parents.

3.5.2. Mobilising family and support groups to manage medicine

In addition to direct encouragement, families drew on broader social networks to support medicine management. Parents described actively engaging with epilepsy charities and peer support groups to manage ASM. Many parents reportedly sought information from multiple sources to inform decisions about medicine. This included epilepsy charities, online forums and family members with healthcare backgrounds. Parents explained that speaking with other families helped them differentiate between medicine side effects and seizure related behaviours, increasing their confidence when discussing concerns with clinicians.

Parents also reported that books, children's programmes and storytelling were used to explain epilepsy and treatment in age-appropriate ways.

“There's like books and stuff as well, children's books as well, which I think is quite good, which we've read to him, not actually talking about medicine itself, but talking about epilepsy and a story as well. So that might be good for the younger children” (Parent 9).

3.5.3. Support and reassurance from healthcare professionals

Beyond family and group support, healthcare professionals also played a crucial role in supporting medicine management. Parents reported that, clear communication, access to specialist nurses, responsive neurology teams, and collaborative decision making strengthened parental confidence and facilitated consistent medicine administration. Across the interviews, paediatricians, neurologists, and epilepsy nurses were described as key sources of information and reassurance on medicine management.

Conversely, limited consultation time and insufficient age-specific information acted as a barrier.

“We just, we don't really, to be honest, it's not, we don't get really much information on medicine, in terms of the more detailed information about the medicine” (Parent 9).

3.5.4. Persistence in overcoming resistance

Despite social support and encouragement, parents' persistence was perceived to influence medicine adherence. Parents expressed that medicine taking was not always smooth or willingly accepted, rather, it required continuous parental persistence. Importantly, persistence was not solely forceful, it also included strategies such as one-to-one time

with the child until the medicine was taken.

4. Discussion

This qualitative study has shown that the barriers and enablers of ASM adherence in children in the UK are medicine formulation, management of medicine, beliefs and experiences and social support. Within these areas, the study also highlighted several less frequently reported influences on adherence, including parental use of rewards, establishing routines, and children's ability to swallow medicine. These findings extend existing evidence by providing deeper insight into aspects of adherence that have previously received limited attention in the literature. Some themes, particularly those relating to medicine organisation and support, were informed predominantly by parent accounts, reflecting parents' central role in managing their child's ASMs. The findings included influences consistent with both intentional non-adherence (e.g. concerns about adverse effects) and unintentional non-adherence (e.g. forgetting doses, formulation characteristics, administration burden and medicine availability). The findings are likely to be most transferable to families of CWE receiving care within the UK National Health Service, where prescribing practices, medicine supply pathways and access to specialist epilepsy services are broadly similar. Transferability to other healthcare systems should be considered, particularly where medicine availability, prescribing regulations, healthcare funding or models of epilepsy care differ. Overall, this study builds on prior research by offering a deeper understanding into areas of ASM paediatric adherence that had previously received limited attention.

The results highlighted that, for children reported to have learning difficulties, consistent medication routines provided stability and reduced anxiety and parents also perceived brightly coloured liquid formulations to be associated with behavioural changes in their children. However, these findings do not establish systematic differences between children with and without learning difficulties. Nevertheless, they highlight the importance of considering individual formulation and routine-related needs and ensuring the inclusion of children with learning difficulties in future adherence research and intervention development.

Trust in the effectiveness of the medicine and concerns about adverse effects were found to influence adherence among children with epilepsy. In some families of children with uncontrolled seizures despite treatment, there was reluctance to administer ASMs, as medicines were perceived as ineffective in controlling seizures. This perception may reduce confidence in treatment and increase the risk of non-adherence. Studies have shown that among children who failed first-line ASM, lack of efficacy and adverse effects are the common factors in treatment discontinuation [21,22]. These findings suggest that families who lack confidence in the effectiveness of medicine for seizure control may be at increased risk of discontinuing treatment. Healthcare professionals (HCPs) should therefore prioritise clear communication about treatment expectations, address concerns about efficacy and adverse effects, and provide ongoing reassurance and support to families, particularly when seizure is uncontrolled. Although evidence suggests that patients and families want this information it is not always routinely provided by HCPs, often due to concerns that discussing adverse effects may negatively impact adherence [23], HCPs should offer early opportunities for feedback if treatment does not appear to be effective.

Availability of ASMs at the pharmacy was identified as a barrier to adherence. Many families express the challenges they encountered in obtaining their child's medicine, including delays and limited availability. In some cases, families were given different brands or formulations when the prescribed medicine was unavailable, which introduced additional challenges for administration. Some parents perceived that changes in brand were associated with increased seizure frequency. The Medicines and Healthcare Regulatory Agency (MHRA) classify ASMs as Category 1, switching and substitution should be avoided as equivalence

cannot be assumed, Category 2, switching should be done with care and Category 3, therapeutic equivalence can be assumed between different brands and generics. However patient factors such as anxiety, risk of confusion, or potential for dosing errors (medicine given incorrectly) should be taken into account when switching between brands [24]. Such changes may also contribute to confusion, reduced confidence, and potential dosing difficulties, particularly in children. These findings are consistent with previous UK based research in which participants reported similar difficulties accessing prescribed ASMs and receiving alternatives brands when their usual medicine was not available in pharmacies [25]. Prescribers should consider adding specific brands or formulations to prescriptions to minimise unintended switching. Healthcare professionals should prioritise continuity of medicine supply by working closely with pharmacies to ensure consistent availability of prescribed ASMs.

The taste of the medicine was a concern for children with many struggling to take unpalatable medicines. Parents described using strategies such as mixing medicines with sweet foods to improve medicine acceptability. While these approaches may provide short term adherence, they may not be sustainable and could introduce additional challenges. There is limited evidence on the effects of mixing medicine with various foodstuffs. Additionally, if the mixture is not consumed fully, the desired dose will not be administered. As altering the method of medicine administration may affect dosing, stability, absorption or modified release properties for some formulations, families should seek advice from their pharmacist or epilepsy team before modifying how ASM are administered.

Beyond taste, some parents perceived that the colour of ASMs influenced their child's behaviour and willingness to take the medicine. The finding contrasts with evidence from a systematic review exploring children's preferences for oral medicines, which reported red and pink as generally preferred colours. However, most of the studies included in the review involved healthy children receiving short-term medicines, limiting the applicability of these findings to children with chronic conditions such as epilepsy. Our findings however align with a previous qualitative study conducted among children with a chronic condition prescribed oral medicines in which Epilim (branded version of sodium valproate liquid) was described as "alarming" in appearance [26]. This highlights the need to consider visual characteristics of medicines when prescribing and designing paediatric formulations.

Medicine-measuring equipment was sometimes not provided or inappropriate for specific dose measurement. Parents reported that syringes for measuring liquid ASMs were not suitably calibrated for the prescribed dose. This sometimes creates uncertainty and increased the risk of dosing errors. The European Medicines Agency guidance, [27] has highlighted that a suitable measuring device may play a pivotal role in accurate dosing and that the lack of this may compromise medicine safety and adherence.

Furthermore, support from healthcare professionals and peer networks were essential to maintain adherence among families with epilepsy. Parents expressed the use of social media forums to seek advice and reassurance when healthcare professionals are not immediately available. However, limited consultation time acted as barrier. Parents reported limited opportunity to discuss concerns or receive detailed information during clinical appointments. As a result, some parents became increasingly reliant on informal sources such as social media platforms, to obtain information about their child's medicine. While these platforms provided timely support, reliance on non-professional sources may have implications for the accuracy and consistency of information, highlighting the need for improved access to timely, reliable guidance from healthcare professionals.

Also, parental persistence involved sustained caregiver effort, negotiation and adaptation to support medicine-taking when children were resistant. While this may support adherence, persistence should not be considered inherently beneficial, as repeated encouragement may sometimes be experienced by children as pressure or reduce autonomy.

5. Strengths and limitations of the study

To the best of our knowledge, this is one of the few qualitative studies conducted in the UK exploring the experiences of both CWE and their parents regarding ASM use. A key strength of this study was the inclusion of children whose parents reported a learning disability. Although the questionnaire did not distinguish between specific diagnoses, this group has frequently been underrepresented or excluded from epilepsy research despite experiencing a higher prevalence of epilepsy than the general population. Child-friendly activities supported engagement and enabled younger children to express their experiences during interviews.

Despite these strengths, participants were recruited through epilepsy charities, which may have preferentially attracted families who were already engaged with epilepsy services, actively seeking information or motivated to share their experiences. Recruitment was also limited to families able to participate in online interviews, potentially excluding those without reliable internet access or suitable digital devices. Furthermore, only English-speaking families were eligible to participate, which may have reduced representation to the experiences of families from other backgrounds. The sample lacked ethnic diversity and included more mothers than fathers, which may have influenced the experiences reported. Of the seven children interviewed, only one was a male, hence, the gender imbalance among the child participants may limit the transferability of the findings. Interviews were conducted online and hence families with no access to a digital device or stable internet connections may have been excluded. Although the approach of conducting this study jointly with children and their parents supported participation and emotional comfort, it may have influenced children's responses despite efforts to ensure children spoke first and parents did not answer on their behalf. Consequently, differences and interactions between child and caregiver perspectives were not explored systematically, as the study aimed to understand family experiences of ASM adherence rather than undertake a formal dyadic analysis.

6. Recommendation for clinical practice

The findings identify several potentially modifiable targets for supporting ASM adherence in children with epilepsy. Formulation-related challenges such as unpleasant taste, medicine volume or size and difficulties with administration, highlight the importance of considering child-appropriate and acceptable formulations when prescribing. Where clinically appropriate and consistent with MHRA guidance [24], prescribers may consider specifying a particular brand or formulation for individual children who experience difficulties following changes in medicine appearance or formulation. Additionally, consideration should be given to the visual and sensory characteristics of medicines, such as colour and taste, when designing paediatric formulations to enhance acceptability (how the child accepts the form of the medicine) and adherence.

Some parents described crushing tablets or mixing medicines with food to facilitate administration. As the appropriateness of these practices is formulation-specific, families should be encouraged to seek advice from their pharmacist or epilepsy team before altering the method of administration. Clearer formulation-specific information within the Summary of Product Characteristics (SmPC) and Patient Information Leaflet (PIL) may also help families manage administration difficulties safely.

These findings identify potential targets rather than evaluated interventions. Future research should therefore determine how formulation acceptability, treatment routines, communication, medicine access, family support and children's involvement can be translated into acceptable and feasible intervention strategies and evaluate their effectiveness in supporting ASM adherence. Future research with a broader and more diverse sample could also explore whether medication adherence experiences differ by gender, age, developmental stage and

other relevant characteristics.

7. Conclusion

This qualitative study identified a range of child-, caregiver-, treatment-, and health-system-related factors that participants perceived as influencing ASM taking among children aged 5–12 years. Formulation acceptability, concerns regarding effectiveness and adverse effects, daily routines, medicine availability, administration challenges, and access to professional and peer support were prominent across the accounts. The findings highlight the need for clinicians to discuss formulation and administration difficulties proactively and to provide families with individualised, age-appropriate information. Given the charity-connected sample, the findings should be interpreted as context-specific.

Declaration of competing interest

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Supplementary materials

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Data availability statement

The dataset from this study is not publicly available due to the potentially identifiable nature of the data and the conditions of participant consent.

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