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Drug-resistant epilepsy and ketogenic diet therapy – a qualitative study of families' experiences

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ABSTRACT

Background: A diagnosis of drug-resistant epilepsy is life changing for a family. Ketogenic diet therapy (KDT) can offer hope when other treatments have failed. However, it often requires a significant change in daily routine and dietary habits. This qualitative descriptive study aimed to explore families' experiences of epilepsy and KDT.
Methods: Parents of a child aged ≤18 years with epilepsy, currently or recently treated with KDT, were recruited from the UK and internationally via UK Ketogenic Diet (KD) centres, charities, and social media. Semi-structured interviews were audio recorded, transcribed verbatim, anonymised, coded using Nvivo (V12), and inductive thematic analysis undertaken.
Results: Twenty-one parents participated. Four themes and 12 subthemes emerged: 1. 'Epilepsy is all consuming' explored the impact of epilepsy on the family. 2. 'KD provides a window to new opportunities' explores the motivators for KDT and positive outcomes. 3. 'The reality of KD' explores day to day life and how families adapt to KD. 4. 'Looking to the future' explores the factors that may make KD easier for families. All were glad their child trialled KD, even when less successful. The importance of a support network including family, friends, charity organisations and the KD team was evident across all themes.
Conclusions: We conclude with five recommendations to help support families in their management of KDT; Improved access to KDT and transition to adult services, access to quality education and support, enhanced variety of KD foods, regular social education and finally consideration of peer mentoring.

1. Introduction

Children with drug-resistant epilepsy experience regular debilitating seizures despite treatment with multiple anti-seizure medications (ASMs) [1]. It is a life-changing diagnosis for the child and their family, requiring an adjustment to a new 'normal', characterised by the unpredictability of seizures and the coexistence of comorbidities [2,3] It is widely accepted that chronic illness, such as epilepsy, presents additional burdens and care needs for parents, increasing their anxiety, stress, and depression [4,5].

Ketogenic diet therapy (KDT) can offer hope to families when anti-seizure medications, surgery or vagus nerve stimulation have failed or are not feasible. It is an effective treatment for children with drug-resistant epilepsy leading to improved seizure control [6–9] and cognition [10]. However, insufficient attention has been paid to how KDT impacts on daily life for families. It requires substantial changes in routine and dietary habits, even for more liberal diets such as the modified KD. Parents or carers lead the preparation and management of KDT including weighing and measuring foods, planning and preparing meals, monitoring ketosis and outcomes. This role offers parents a sense of control and involvement in their child's care, however the extra workload may create additional stresses and challenges for the family. This study explores the experiences of families using three different types of KDT; modified, classical and MCT KD. Collectively they have the aim of establishing ketosis and optimising clinical outcomes so all will be referred to as KDT.

As early as the 1920s [11,12,13], parents were recognised as playing an essential role in KDT management. Yet little is known about their experiences and perspectives regarding the impact of KDT on their child and wider family. Family life is busy and anecdotally many parents

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report feeling overwhelmed and daunted when introducing KDT. Relatively few studies have examined parent experiences and views during this time. Williams [14], together with three other parents shared their child's story of epilepsy and KDT. They recalled the despair of witnessing their child seize uncontrollably, the difficulties of accessing KDT, and the anxiety they felt when weaning from KDT after years of successful treatment. The accounts provide helpful insights into some key themes for families, but lack depth owing to their short narrative nature. More recently, parents reported stress as the biggest contributor to their emotional or mental health and well-being. However, this was attributed to their child's overall health and not just as a result KD [15].

Webster [16,17] investigated the experiences of parents and siblings with childhood epilepsy and with Gabe [18], examined the identities of parents when using KDT for their children. Parents were able to maintain their identity as good parents by medicalising KD and treating food as medicine, despite the restrictions KD imposed on their child.

1.1. Objective and significance

This study aimed to build on these earlier findings by conducting in depth interviews with parents to broaden understanding of the impact of epilepsy and KDT, providing insight into parents and families' experiences. Our ability to provide families with appropriate support will be enhanced with a deeper understanding of their experiences from diagnosis through to the management of KDT.

2. Methods

This qualitative descriptive study was carried out as part of the development of a core outcome set for childhood epilepsy treated with KDT [19,20], registered with the Core Outcome Measures in Effectiveness Trials (COMET) Initiative [21] and the study protocol published [22].

We applied an interpretive descriptive approach to explore families' experiences of treating epilepsy with KDT. Interpretive description departs from other typical qualitative descriptive approaches as researchers interpret the data rather than simply describing it, understanding the participants views and experiences and situating the findings within existing research and clinical knowledge [23]. The researcher's technical knowledge and clinical experiences are a major source of insight, used as a valuable instrument in the research rather than a bias as is often thought to be the case [24]. The study fulfils key criteria for quality in qualitative research as defined by the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Appendix 1) [25].

2.1. Sampling and recruitment

Participants were eligible if they were a parent or carer to a child aged 0–18 years with drug-resistant epilepsy treated with KDT or had weaned from KD in the past year, and were English speaking. Children with co-morbidities were not excluded. Maximum variation sampling strategies were employed to ensure optimal diversity in terms of the following characteristics: epilepsy diagnosis, age, home country, type and duration of KDT and response to treatment with KDT.

Participants were recruited from across the UK and internationally from three sources using social media posts, flyers, posters and health professional's invitations:

1. Nine UK KDT centres (UK participants)
2. Charities: Matthew's Friends, Young Epilepsy, Epilepsy Action, (UK and international participants)
3. Epilepsy – the Ketogenic Way: a family support group on Facebook (UK and international participants)

2.2. Data generation

Written consent was taken prior to the interviews and participants were reminded that they could stop the interview or withdraw from the study at any point. Interviews occurred between January and June 2020 with a median duration of 72 min (35–131 min) either online, via telephone or in person, conducted by JC, a registered dietitian and doctoral researcher with approximately 12 years' experience with KDT. This may have increased the risk of observer basis, however this was mitigated by ensuring the wider research team and study advisory group were consulted in the planning of the interview schedule. Parents hopes and expectations of KDT, daily experiences, outcomes of treatment and strategies to manage KDT were explored using a semi-structured interview with a range of open questions to facilitate parent led discussion, ensuring consistency in the core questions asked while allowing individual views and perspectives to be expressed (Table 1). Demographic data was collected (Table 2). Participants were aware that the interviewer had worked as a ketogenic dietitian but was speaking to them in a research capacity, in pursuit of a PhD and no participant was or had been treated in the past by the interviewer. A reflective research diary was used by the researcher to document thoughts and findings post interview to support later analysis.

2.3. Data analysis

Participants were anonymised with a number, prefixed with FP (female participant) or MP (male). Interviews were audio-recorded, professionally transcribed (intelligent verbatim transcription), and uploaded to NVivo 12 (QSR International, Burlington, US) for analysis.

The transcripts and audio recordings were reviewed several times to become immersed in the data, [26,27] gaining understanding and insight into the context of the discussion. Thematic analysis was undertaken to investigate the detailed contextual descriptions of families' experiences [28].

Data was minimally theorised, providing an account of the experiences of families, what it meant to them, what they think and believe. An inductive approach to coding was adopted, deriving codes that reflected concepts emerging from the data. Initial coding and identification of early themes was performed by JC and then further refined through regular review and discussion with TP (an experienced qualitative researcher). The final themes were agreed by all authors.

2.4. Patient and public involvement and engagement (PPIE)

Two parent partner co-investigators (EW, VA) who had personal experience with epilepsy and KDT joined the research team. In addition to their experience as parents, they also supported other families with

Table 1
Semi-structured interview schedule.

	Questions
1.	Please start by telling me the story of your child's epilepsy
2.	Could you tell me how your child's epilepsy has affected you and your family?
3.	Thinking back to before your child started ketogenic diet, can you tell me what your expectations or hopes of the diet were?
4.	Were those expectations delivered? (what has changed with ketogenic diet?)
5.	Can I ask, how did that make you feel?
6.	Has that changed - do you still feel that way now?
7.	As you are aware we are interested in the results or outcomes that parents think are important to assess in clinics and research, what results do you think are important when using the KD?
8.	If you were asked to prioritise, what would be the most important result or outcome?
9.	Can you tell me about the day-to-day management of the KD?
10.	What might help to make KD easier for families?
11.	Do you think a buddy or mentoring programme would be helpful where parents support each other with KD?

Table 2
Participant characteristics and demographic data.

Participant	Type of interview	Country of residence	Gender parent	Gender child	Age of Child (Y, M)	Diagnosis	Type of KD	Feeding route	KD therapy duration (Y, M)	Response to KD	ASMs trialled pre KD
FP1	Telephone	UK	F	M	12y 3m	Juvenile epilepsy	MKD	Oral	6m*	Seizure reduction	2
FP2	Video call	UK	F	M	5y 10m	Tetrasomy 18p	MKD	Oral	6m	Seizure reduction	4
FP3	Telephone	Ireland	F	F	12y 11m	Benign focal epilepsy	MKD	Oral	4m	Seizure reduction	7
FP4	Telephone	UK	F	M	3y 3m	Infantile spasms	Classical →MKD	Oral	1y classical 1y MKD*	Seizure free	3
FP5	Video call	UK	F	M	8y 7m	Doose syndrome	Classical	Oral	4y	Seizure free	3
FP6	Telephone	UK	F	M	9y 7m	Drug-resistant epilepsy	Classical	Oral	2y*	Seizure reduction	4–5
FP7	Telephone	UK	F	M	17y 2m	Idiopathic generalised refractory epilepsy	MKD	Oral	5y 3m	Seizure reduction	6
FP8	In person	UK	F	F	12y 9m	Subcortical band heterotopia	Classical	Oral	2y 4m	Seizure reduction	4
FP9	Video call	UK	F	M	5y 6m	Myoclonic astatic epilepsy	MKD	Oral	1y 10m	Seizure free	5
FP10	Telephone	New Zealand	F	M	14y 7m	Drug-resistant epilepsy	MKD	Oral	4y 6m	Seizure free	6
FP11	Telephone	USA	F	M	2y 4m	Dravet syndrome	Classical	Oral	1y 2m	Seizure reduction	1
FP12	Telephone	New Zealand	F	M	13y 4m	Lennox Gastaut syndrome	MKD	Gastrostomy & oral	6m	Seizure reduction	4
FP13	Telephone	UK	F	M	2y 9m	*PLCB1* related epilepsy	Classical → MKD	Oral	1y classical 8 m MKD	Seizure free	3
FP14	Telephone	UK	F	M	3y 7m	Angelman Syndrome	MKD	Oral	1 y 2m	Seizure reduction	3
FP15	Telephone	Australia	F	F	5y 0m	Doose syndrome	MKD	Oral	1y 10m	Seizure free	2
FP16	Telephone	Australia	F	F	6y 3 m	Drug-resistant epilepsy Drug- resistant	MKD	Oral	6m	Seizure free	-
				F	9y 0m	epileps	MKD	Oral	6m	Seizure free	4
FP17	Telephone	UK	F	F	2y 3m	Dravet syndrome	Classical	Oral	7m	Seizure reduction	3
FP18	Telephone	UK	F	M	12y 11m	Complex drug-resistant epilepsy	MKD	Oral	6m	Seizure reduction	6
FP19 § MP2	Video call	UK	M F	M	7y 9m	Drug-resistant epilepsy	Classical	Oral	1y 10m	Seizure reduction	4
MP1	Telephone	UK	M	F	14y 6m	Drug-resistant epilepsy	MCT	Oral	2y 6m*	Seizure free	4

FP: female participant, MP: male participant, *Weaning in progress or weaned from KD, § joint interview with participant FP19 and MP2, MKD: modified ketogenic diet, MCT: medium chain triglyceride ketogenic diet.

KDT at Matthew's Friends, where they served as trustees. During an early patient and public involvement consultation, parents of children treated with KDT emphasised that time constraints and competing demands would pose the greatest challenges for participating parents. Interviews were therefore offered seven days a week from early to late, via telephone, video call or in-person visit to the parent's home (UK only).

2.5. Ethical approval

Ethical approval was granted by the National Health Service Health Research Authority (London-Surrey Research Ethics Committee, reference 19/LO/1680).

3. Results

3.1. Sample characteristics

Thirty-eight parents registered their interest to take part and 21 parents were recruited and interviewed (19 individuals and one couple), representing 21 children as one mother had two children following a KD. No participants withdrew. Of the 17 participants not recruited, four were unable to participate owing to; hospitalisation, family bereavement, Coronavirus pandemic pressures and a response lost in junk folder. Two participants were ineligible owing to age or duration weaned from KD. Eleven were lost to follow up.

The modified ketogenic diet was most often used ($N = 13$), followed by the classical KD ($N = 6$) and medium chain triglyceride KD ($N = 1$), all orally fed except for one child having top up gastrostomy feeds. Children (67% male, 34% female) ranged in age from 2–17 years (median 8yrs 7mths) and had trialled between one to seven anti-seizure medications (median 4) prior to commencing KD therapy. The duration of KD treatment ranged from 4 months to over 5 years (median 1 yr 10mths), during which nine children achieved complete seizure freedom and the remaining 12 experienced seizure reduction. The precise percentage reduction in seizure frequency was hard to quantify, but we estimate based on parental reports that four children experienced less than a 50% reduction, while the remaining eight children saw a reduction of 50% or more.

Most participants lived in the UK ($N = 15$). International participants were recruited from New Zealand ($N = 2$), Australia ($N = 2$), America ($N = 1$) and Ireland ($N = 1$). Advertising by charities on social media and in a closed parents' forum proved to be the most successful recruitment strategies ($N = 17$). Table 2 summarises demographic data for parents and children together with treatment characteristics.

3.2. Thematic summary

Thematic analysis identified four broad themes and 12 sub-themes, mapped in Table 3 together with illustrative codes and quotes. A narrative overview will follow of the journey families face from diagnosis of epilepsy, accessing KDT, managing daily life on KDT and finally how KDT might be made easier for families.

3.2.1. Theme 1: epilepsy is all consuming

This theme explores the impact of drug-resistant epilepsy on the family, the uncertainty and their fight to access KDT. All parents described the all-consuming nature of their child's clinical condition and the difficulties the family faced.

3.2.1.1. Impact of epilepsy on the family. Parents recalled first seizures, initial diagnosis, and the 'spiral' that followed as they struggled to come to terms with and navigate their family's new reality. Watching their child seize regularly was *'scary, devastating, worrying, and exhausting'*. Parents physical health, mental health and wellbeing were affected with many struggling to sleep (quote 1). Work and careers were often affected, especially for mothers who took career breaks, worked part-time or left their job to care for their child.

Epilepsy affected children's physical health, cognitive development and ability to learn, social skills, and Quality of life (QoL) in many ways (quote 2). Parents' explanations of what constitutes a good QoL varied, but FP18 described it as *'a normal type of life or being able to do activities of daily living'*. It was felt children were missing the opportunity to participate in everyday life because of experiencing uncontrolled seizures on a regular basis.

Parents had strong concerns about the adverse effects of ASMs with all but one describing the side effects children experienced. Cognitive function, appetite, mood, behaviour, sleep, and mental health were affected, with one child experiencing suicidal thoughts. Children were dazed and disengaged, often referred to as being in *a* zombie-like state or experiencing brain fog (quote 3). It is important to interpret this data with caution as these are parent observations over prolonged periods of time. However, it provides insight to the breadth of adverse effects that children receiving polytherapy experienced. It was difficult to ascertain if the adverse effects were solely attributable to epilepsy, ASMs or possibly a combination of both. Nevertheless, parents were highly motivated to wean their children from ASMs in an effort to reduce symptoms. Over half of parents interviewed referred to their child's siblings and how epilepsy had negatively affected them. There was a general sense of siblings having to be more responsible and watch out for their brother or sister with epilepsy. This support was often invaluable for parents, but it created additional worry that they were neglecting their children by not paying them enough attention or expecting too much of them (quote 4).

3.2.1.2. Uncertainty of epilepsy. Parents faced many uncertainties, a constant unknown that manifested itself in day-to-day life. There was a sense of grieving for what might have been in the future, as it became clear that life would not turn out as planned (quote 5). They searched for answers and solutions to identify their child's diagnosis and potential treatments. As one mother (FP8) put it, she was *'a mother on a mission.'* This drive to find the answer may have been a coping strategy to address a sense of helplessness, to bring some order to the uncertainty faced.

3.2.1.3. Fight for my child. Almost half of parents described how they had to initiate a discussion about KDT with their child's paediatrician or neurologist. Some managed to access KDT quite quickly but many parents reported the fight they faced for their child to access KDT (quote 6).

3.2.2. Theme 2: opening the window to new opportunities'

This theme explores parents' motivations for trialling KDT, the positive results their children experienced, and the impact these outcomes have had on their families. Drug-resistant epilepsy can bring feelings of frustration, uncertainty, and helplessness when ASMs fail to control seizures. However, KDT offered parents hope and the opportunity to possibly regain some control in the management of their child's epilepsy. One mother (FP12) captured the essence of this theme when she described KDT as *'opening the window':* it was providing her son with the opportunity to unlock his potential and that offered her hope for the future.

3.2.2.1. Hopes and expectations of trialling ketogenic diet therapy. Several factors influenced parental expectations, including the severity of the epilepsy, associated comorbidities, and timing of KDT during the treatment pathway. Parents expectations can be broadly grouped into seizure related and non-seizure related outcomes. Most participants hoped for improvement in seizure control. They also hoped for reductions in dosage and number of ASMs, developmental and cognitive gains, improved social and emotional functioning and overall QoL (quote 7). Most parents felt their expectations of KDT were met or

Table 3
Mapping of themes, subthemes, codes and illustrative quotes

Theme	Sub Theme	Code	Quote no.	Quote and Participant Identifier
1. Epilepsy is all consuming	Impact of epilepsy on the family	- Impact for parents - Impact for child - Impact for siblings	1	*'I guess if you asked what the impact of seizures on our life was, it was our life for quite a number of years. That's what we read and that's what we did, and it was all based around the children. My husband and I didn't really get a look in. Plus, we're at the hospital every two weeks with appointments. We worked full time throughout that as well, both of us, so it was quite a lot going in in the house.' (FP10)*
			2	*'I don't know how to quantify it really…he's been diagnosed so long the seizures themselves…. don't really bother us so much, it's the learning disabilities and the things that come with it that do… A lot of what comes with it, the learning disability impacts absolutely everything.' (FP7)*
			3	*'..You start looking at quality of life as well, because you're doing all these medications, you're going up, you're being advised perhaps if you want to go up, go up a bit higher, you want to go up to this. So, you're going up and you're seeing the impact in the behaviour, the education. Just everything really, quality of life. But they're wiped out and they're a bit of a zombie. That's not fair either.' (FP6)*
			4	*'They really do look after her. …I think actually we take it harder than them. I think we worry that they are missing out…I don't feel they hold any grudges against us which is what you worry about.' (FP17)*
	Uncertainty of epilepsy	- Day to day uncertainty - Future uncertainty - Searching for the answer - Difficult decisions - Other people worse off	*5*	*'So yeah, it kind of changes the way that you attack everything. It's kind of a grieving period of, well our lives are not going to be the way we thought they were….Not being able to even envision or plan anything concrete – I know technically you can't for any kid – but it's just extra hard here.' (FP11)*
	Fight for my child	- Unsupportive health professionals - Delay in accessing KD	6	*'Everything's a battle, that's one thing we learned. Nothing is easy, nothing's straightforward. A lot of people are nice, and they mean well, but it's a paid job, they don't live it. I'll do whatever it takes for X, I don't care." (FP14)*
2.Opening the window to new opportunities	Hopes and expectations of KD therapy	- Side effects of ASMs are a motivator for KD - Health professionals who encourage KD - Possibility of progress - Evolving expectations	7	*'So any form of [seizure] reduction, but for me as his mum I just wanted any improvement in his quality of life. I wanted him to just be able to be happy and live. When I've got a child who can't put one foot in front of the other, just sitting on the sofa drooling, can't even focus on the telly or communicate, that's not living and that's what medication had done to him. Not a chance.' (FP19 MP2)*
	No longer a passenger	- Parent's sense of purpose and control	8	*'it [KD] was something that we could do. It would take work and effort from us, whereas everything else was just kind of out of our control…. We feel like we're doing everything we can do and give you a bit of control in the scenario, that you've got no control over.' (FP11)*
	I've got my child back	- Benefits of KD - Parent's feelings in response to KD - Positive impacts on family life	9	*'after about two days, it was like, oh my god, he's seizure free… It was just amazing, so we had our old X back. His personality went back to what it was when he was about six, and we just saw the glimpse of the X he used to be'. (FP10)*
			10	*'Be that little bit proud, yes, you're actually doing stuff now.. it's almost opening the window up to him learning those new skills that he never had that possibility before**.**….the KD has just given me a bigger window of hope for there's still options out there for him.' (FP12)*
			11	*'Oh, it's completely changed our lives, completely and utterly. People don't understand it. I think people at school don't understand because they didn't see him when he was having seizures'. (FP9)*
3. The reality of KD therapy	KD can be challenging	- Time consuming and rigid - Unindividualised KD plans	12	*'Its monumental, its huge…the impact that the diet has made on his life in a positive way – don't get me wrong though, it's really hard, our life is not like most other people. We don't have a normal life but it's so worth it.' (FP19, MP2).*
		- Changed family eating habits - Missing favourite foods	13	*'Socially it's awkward, financially it's a bit hmm, shopping's a bit hmm, but at the end of the day there's no chocolate bar out there that's worth going back to how he was.' (FP7)*
		- Feeling different - Cost - Access to suitable foods and drinks - Eating out and holidays - Lack of understanding from others - Difficult to trust others with KD management - Managing illness	14	*'But the downsides are manageable and minor compared to impact… It's amazing. The diet gives you the possibility - the limitations are so minor compared to the possibility to live a normal life. I believe this is valid for kids and adults. It gives you the opportunity - the limitations are not that frightful. It gives you the opportunity to live. That's it, to live, because the other one is existence. It's not living.' (FP5)*
	The evolving KD mindset	- Starting out - Adapting to KD - It gets easier with time - The importance of firsts	15	*'I mean, the first time we manage to go out for a meal, that felt like a win. So we went to Nando's and we just had plain chicken and broccoli. But, yeah, that felt like, oh actually we can do normal things you know?..We've had family to stay and we've managed to do fry ups and his hasn't looked noticeably different to anybody else's. So with a bit of planning and prep you can have food and join in and feel part of a social occasion.' (FP18)*
	A support network is crucial	- Charities - Health professionals - Family	16	*'I attended two to three cookery days, yeah just to meet other people actually who were on a diet. Because that was one of the biggest things, you feel quite isolated and nobody else really understands…so just to have that*

(*continued on next page*)

Table 3 (*continued*)

Theme	Sub Theme	Code	Quote no.	Quote and Participant Identifier
		- Peer support - Online networks		*link to a few people you meet on the cookery days was really invaluable.' (FP6)*
			17	*'We have her [dietitian] on a pedestal because, well, we- maybe not directly, but we actually do feel like she's saved X's life, and that she's given X the opportunity to have as normal an adulthood as she could possibly have. So, yes, we kind of owe her everything, I guess.' (MP1)*
4. Looking to the future	Enhanced awareness and understanding	- Health professionals - Family and friends and general public	18	*''I was speaking to a lady in work, and her son's got epilepsy, and I mentioned about the diet, and she didn't know anything about it either. So, I told her about it, and said look at these…I think some people just don't know it's out there, do they?..It's empowering parents with the knowledge that it's out there' (FP13)*
	Variety and access to ketogenic foods	- Prescribable products - Shop bought foods and drinks	19	*'I think having more access to ready meals, stuff that you could buy off the shelf, or on prescription ideally on prescription.' (FP8)*
	Support and education	- Social education - ketogenic cookery days - Peer mentoring	20	*'We had a keto cookery workshop on Saturday..That's the first one we've had. It was fantastic, not just helpful. Absolutely amazing. So many little tips that I picked up for her.' (FP8)*
		- Children's support group	21	*'So to have somebody [a keto buddy or peer mentor] that – yes that's, come on, keep going, it's worth it, and we've all been there, we've all been there, you'll get through to the other side, just something like that, that actually has the experience of starting the diet and knew about the constipation, they knew about the reflux and all their suggestions. That would have been really good actually yes.' (FP13)*
		- After KD what's next; trepidation of weaning from KD and transitioning to adult care	22	*"Yes, I wasn't keen, they've pushed more than I have. I think it's taken me two years to get to okay, let's give it a go, put it that way… I'm terrified and excited at the same time. It would very much be nice to be able to just go out for a meal with the family, to have a social experience…Yes, I am nervous about it, I'm very, very nervous that when we get to a point where he's off it [KD] completely and we start introducing foods back that he's going to go back to how he was. I am at the point now where I don't think I can do that again, I really don't think I can do that again. So that scares me. I'm hoping, because you are supposed to stay on it for two years and then the benefits are supposed to stay and that's it, I'm hoping that that's going to be the case." (FP7)*

exceeded, however two families were disappointed with the level of seizure control gained.

3.2.2.2. No longer a passenger. A strong subtheme was the need parents felt to take an active role in managing their child's epilepsy and to gain control over their situation (quote 8). KDT is a medical diet with potential to cause side effects. Yet, parents derived satisfaction from the knowledge that the diet was *'just food'*, and not an additional medication. Food in essence was becoming medicine for their child. KDT is a significant undertaking, even when highly motivated and the responsibility of preparing every meal and snack correctly can be daunting. However, there was a sense of accomplishment and pride amongst parents when they felt they were mastering KDT. Likely, their self-efficacy was improving, as their confidence and skill grew. This enhanced their sense of control of their situation. However, with that control comes additional pressure to *'get it right'*. While the uncertainty of drug-resistant epilepsy may have improved, everyday life was more complex which may have added to the stress and pressure parents felt.

3.2.2.3. Benefits of ketogenic diet therapy. The positive impacts of KDT can be divided into seizure-related and non-seizure-related outcomes, although they are often interrelated. It was common for parents to share the sentiment: *'I got my child back'* when asked if their expectations of KDT were met (quote 9). The benefits were undoubtedly positive for the child with drug-resistant epilepsy, but also for the wider family (quote 10). All children experienced a reduction in seizure frequency, while nine (42%) achieved complete seizure freedom. Achieving seizure freedom was described as *'a dream come through'* as it positively impacted upon other outcomes. Non-seizure-related outcomes improved including behaviour, alertness and concentration. Children were described as being more clear headed and engaged at home, when interacting with siblings and during school activities (quote 11). Friends, health professionals and teachers noticed the changes which parents found reassuring and rewarding, positively reinforcing their efforts with KDT.

3.2.3. Theme 3: the reality of ketogenic diet therapy

Although KDT can result in positive outcomes for families, there are challenges in the daily management, which are explored in this theme together with strategies parents used to overcome these (quote 12).

3.2.3.1. Ketogenic diet therapy can be challenging. A commonly held view was that KDT is time consuming, rigid and inflexible, especially in the early months when there is so much new information to take in. Some participants experienced additional stress, pressure, and anxiety during this time.

However, not all experienced challenges, a small minority were surprised at how well they adapted to KDT and attributed this to their child being younger and/or compliant. Few parents reported adverse effects associated with KDT. Parents were motivated to overcome challenges and make the necessary sacrifices to maintain a KD for their child (quote 13). Ultimately, they felt it worthwhile and the same was true for parents whose child had achieved some improvement in seizure control and complete seizure freedom (quote 14).

3.2.3.2. The evolving KD mindset. Over the course of interviews, 'the evolving KD mindset' emerged as a subtheme, exploring how parents' mindsets changed to effectively manage KDT. By doing so, parents were able to achieve a greater sense of control over their child's epilepsy management, a concept closely associated with the subtheme "no longer a passenger". It appears that parents felt they were on a journey with KDT, initially trepidatious but optimistic, gradually developing their confidence and skills, overcoming challenges along the way. Parents were faced with new ways of thinking about food, the ingrained principles of a low-fat healthy diet no longer applied and they *'picked their battles'* with regard to food choices. Many described how they threw

themselves into the KDT education and preparation sessions and how over time the KDT became easier. As parents became more comfortable with KDT, their confidence to try new things improved, such as eating out for the first time and going on holidays (quote 15). Firsts such as these were extremely formative, as they contributed to their sense of achievement and increased self-efficacy, which in turn enhanced their confidence and ease with KDT.

3.2.3.3. A support network is crucial. A support network was commonly viewed as crucial to help families cope with KDT. This network included family members, friends, carers, families with shared experiences, KD charities and the keto multi-disciplinary team. Some of the most valuable support was provided by those who listened and made an effort to understand and assist the family. Connections with families with shared experiences were particularly valued and these were facilitated by keto charities via online forums and groups or social events like coffee mornings or charities and medical nutrition companies facilitating keto cookery days (quote 16).

Parents welcomed the support and motivation they received from their keto team and in particular; timely responses to their queries, monitoring the risk of adverse effects and bespoke recipes and meal plans (quote 17). Interestingly, parents valued dietitians attempts to understand their experience by trailing the KD. However, issues arose when parent's felt unheard, had to wait for long periods for follow up or were provided with recipes or meal plans which they felt would not work for their child.

3.2.4. Theme 4: looking to the future

Having gained a deeper understanding of KDT's impact on families, theme four aimed to identify factors that may make KDT more manageable for families. In particular, how families could be more effectively supported with KDT and inclusion of parental suggestions into recommendations for the keto community to consider. During the interviews, parents were asked to envision what it would be like if they had a magic wand that could make KD easier. They shared experiences, ideas, and strategies, which were analysed and grouped thematically.

3.2.4.1. Enhanced awareness and understanding of ketogenic diet therapy. Some families were not aware of KDT prior to their neurology team suggesting it, which raised the concern for some that if they had not been informed, their child might never have accessed KDT. As one mother stated *'it's about empowering parents with the knowledge that it's out there' (FP13)*. A number of families experienced significant delays in the initiation of KDT, as illustrated by the median number of four trialled ASMs, which is double that suggested in international expert group recommendations [29]. Several parents expressed frustration, anger, sadness, and disappointment regarding what could have been achieved had KDT been initiated earlier. It was hoped improved awareness and understanding of KDT amongst paediatricians, epilepsy nurses, and neurologists would result in fewer families having to wait so long for a referral to a specialist keto team.

3.2.4.2. Variety and access to ketogenic foods. Time was one of the greatest challenges of KDT raised by parents; the time required to plan and calculate recipes, shop for special ingredients, and prepare meals. Consequently, parents would welcome improvements in the convenience of KDT, including a greater variety of prescription medical nutrition products and store-bought options (quote 19).

3.2.4.3. Support and education. This subtheme examines parent perspectives on what constitutes quality support and education for families. There is significant overlap with the earlier subtheme 'a support network is crucial' particularly in relation to the support that KD charities and the keto team provide. Parents described the practical and emotional support that charities such as Matthew's Friends, Daisy Garland, The

Table 4
Recommendations to support families with the management of ketogenic diet therapy.

Recommendations	Actions	Stakeholders to contribute
1. **KDT should be more easily accessible for children, and they should be able to transition to adult KDT services if necessary**.	• Increase awareness of the evidence supporting KDT amongst non keto professionals via CPD webinars, education days, patient testimonials, local outreach and collaboration. • Liaise with our colleagues in adult epilepsy services to support business case development for growth in services. • Participate in initiatives that have a national and international reach in reviewing or setting epilepsy research and treatment priorities, such as consultations and evidence reviews conducted by NICE and partnership priority setting surveys.	• Keto teams • KD charities • Ketogenic Dietitians Research Network • International Neurological Ketogenic Society
2. **Children and their families should receive quality support and education prior to and during KDT**	• Keto teams to take a holistic patient-centred approach to care, considering a variety of seizure and non-seizure related outcomes of KDT. • Connect families with KD charities and the range of excellent resources and services they offer. • Provide emotional support for parents, especially when approaching the time to discontinue KDT.	• Keto teams • KD charities
3. **Children and their families should have opportunities for social education and learning**	• Consider the ability to offer group education sessions in the preparatory phases of KDT where families can meet and learn together. • Offer opportunities for families to meet and learn together in an informal setting such as keto cookery sessions, coffee mornings or informal virtual meetings.	• Keto teams • KD charities • Medical nutrition companies
4. **Explore the feasibility, costs and perceived need to develop a peer mentoring programme for parents new to KDT to receive support from experienced parents**	• Further explore the perceived need and feasibility of a peer mentoring programme via a focus group with parents and professionals.	• CORE-KDT research team • KD charities
5. **Expand the range of ketogenic foods, both on prescription and store-bought to improve the convenience of KDT for children and families.**	• Medical nutrition companies to continue to broaden the range of keto products available. • It is challenging to access and influence the wider food industry but keto teams and KD charities	• Medical nutrition companies • The food industry • Keto teams • KD charities

(*continued on next page*)

Table 4 (*continued*)

Recommendations	Actions	Stakeholders to contribute
	to be responsive in supporting parents to identify suitable keto friendly foods.	

Charlie Foundation, and Young Epilepsy provide. There was a recurring theme regarding the importance of supportive health professionals who listened and worked collaboratively with parents. They emphasised the importance of a holistic approach to supporting families to access and manage KDT, as well as ensuring that a variety of optimal outcomes are considered. FP8 described this as *'looking at the whole child and how everything impacts'*. FP19 and MP2 expanded on this by encouraging health professionals *'to look beyond the numbers'*.

Parents enjoyed and valued keto cookery days where they met with an experienced keto chef, other families, and a dietitian. The sessions could be considered a form of social education where parents could practice recipes, receive hints and tips and share their experiences with others in a relaxed learning environment (quote 20). When asked if a peer support system like a mentor or 'keto buddy' would be helpful, many parents agreed. It was felt that they could share their real insights as families who are living KDT (quote 21). Interviewees, however, emphasised the challenges the initiative might face, such as the need for experienced mentors at each stage of KDT and the increased workload for mentors.

The need for support from the keto team extends to the final stage of KDT, that is weaning from the diet and returning to a more typical, standard dietary intake. It is common to consider this after two years of treatment with KDT [29], and usually the positive outcomes gained on KD are sustained after returning to a normal diet. However, the timing should be determined by the keto team and the family, rather than the family feeling pressured to discontinue the KD. Parents understandably often experience mixed feelings and emotions; it can be challenging to consider stopping KDT after successful treatment and a range of positive outcomes have been achieved (quote 22).

3.3. Recommendations to support families with the management of ketogenic diet therapy

Parents perspectives have helped to shape the five recommendations presented in Table 4. Implementation of these recommendations is proposed through a number of actions and the stakeholders who may be best positioned to assist are identified.

4. Discussion

This qualitative descriptive study aimed to explore how families experienced epilepsy and KDT as told by parents. Their accounts revealed four main themes and twelve subthemes, spanning the period from the diagnosis of epilepsy to the use of KDT as a therapeutic intervention and finally, weaning from KDT. The findings demonstrate that KDT can provide parents with a sense of control over an unpredictable situation, and when successful offers significant benefits to the child and family.

While much is understood about the experiences of families with epilepsy, only one other research group has conducted similar qualitative research addressing epilepsy and KDT. [18,30] However, this was from a sociological perspective focused on the meaning of food within the family and did not address the practical aspects of KDT. Consequently, this study builds upon the work of Webster and Gabe by exploring in greater detail, the practicalities of KDT, benefits for families and potential improvements to future KDT management.

Drug-resistant epilepsy was characterised by persistent and uncontrolled seizures, an unstable condition that created uncertainty for parents. Webster [17] described this as 'a cycle of uncertainty' marked by day-to-day uncertainty, future uncertainty, and symptomatic uncertainty. Several examples were similarly reported by parents in this present study. They worried about their child's diagnosis, treatment options, when the next seizure would occur and what the future might hold. Unsurprisingly, parents of children with epilepsy, particularly mothers [31] have higher rates of stress, anxiety and depression owing to the additional burden of care associated with having a child with a complex illness [4]. There is often no respite from the all-consuming and unpredictable nature of their child's epilepsy.

As parents became aware that their child's future would not unfold as they anticipated, they described grieving the loss of what might have been. Dyson and Fewell [32] suggested that parents are dealing with the inevitable loss of the image of an 'ideal child'. The diagnosis of epilepsy likely intensifies these feelings and may result in a period of mourning, described as a state of chronic sorrow. This can be a long-term, cyclical sadness or grief experienced by parents and caregivers in response to a situation with no predictable end [33,34], independent of epilepsy severity and other comorbid conditions [35]. To help manage feelings of chronic sorrow, parents need to develop ways of coping with their child's epilepsy.

The subtheme 'no longer a passenger' illustrated how KDT provided a problem-focused coping strategy. It offered hope that treatment could be successful and gave parents the opportunity to take the lead in the treatment's provision. Parents with more positive attitudes towards epilepsy have been found to use more positive coping behaviours like seeking social support, strengthening family relationships and being optimistic about life in general [36].

KDT may help parents to have a more positive attitude and optimism about their children's future. While they acknowledged that it would be different from the normalcy they had originally anticipated, there remained positive outcomes. With time, parents' confidence grew, and pride in their ability to attain the expertise and skills required to cope with epilepsy and KD [37]. This was evident in the subtheme 'the evolving KD mindset'.

Children had been treated with a median of four ASMs (one to seven) prior to referral for KDT, in spite of the recommendation that KDT is trialled after two failed ASMs [29], so most families had experienced drug-resistant epilepsy for an extended period. As a result of the delay in access to KDT, parents experienced feelings of helplessness, anger, and frustration, similar to those shared by four families when recalling their experiences with KDT [14]. Parents questioned why KDT had not been offered earlier and how different their child's condition might have been. It is likely that parents experience multiple emotions during those first consultations, so it is essential that keto teams listen to families' prior experiences and acknowledge these emotions. The needs of parents should be considered, as well as the support they may require to adapt to new coping strategies. In the same way, parents need support to help guide their expectations and hopes regarding KDT to address any misconceptions that may compound existing feelings of helplessness. As health professionals, it is our responsibility to take the time to explore individual hopes and expectations with parents.

The goal of KDT for childhood epilepsy is to improve a broad range of seizure and non-seizure-related symptoms and, ultimately, to improve global QoL for children by enabling them to build upon their existing strengths. The theme 'opening the window to new opportunities' demonstrated ways in which children benefited from KDT, which included learning new skills, engaging in activities, and building and maintaining social relationships. In a small study of 12 parents, an unvalidated tool was used to explore their expectations regarding KDT and what would constitute improved QoL for them and their child [2]. The outcomes which led to improved overall QoL for children and parents are similar to those described in our study. These included the child being happy and smiling again, improved alertness and recognition of those around them, developmental progress, reduced seizures,

reduced ASMs and toilet training. More recently, an online survey distributed via social media platforms assessed 192 parents perspectives of KDT. The median score for QoL was 9 on a scale of 0–10 (10 being much improved), which suggests parents felt their children's QoL was much improved when treated with KDT [38]. Although, this study was limited by the lack of a comparison baseline score of QoL prior to KD. Given the reported improvements in QoL it is not surprising that treatment with KDT has been conceptualised as a 'saviour' for children, particularly for those who experienced a reduction in seizures and emergency hospital admissions [30]. Similarly, parents in this present study described the sense of 'getting their child back'. Despite the challenges, they were able to establish a sense of normalcy for their child and family through KDT. Interestingly though, it has been observed that 'the goalposts can shift' over time where parents sub-consciously increase their expectations of KDT, overlooking the positive achievements gained [2]. It is important that keto teams explore these evolving expectations and encourage parents to reflect upon the gains achieved with KDT to support ongoing motivation.

Woodgate et al. [39] describe a state of intense parenting, where parents of children with complex care needs took on more roles than parents of healthy children and they had to work more intensely at these roles. Theme 1 'epilepsy is all consuming' illustrated how parental health and well-being are often deprioritised as they focus on caring for their child with complex needs, coping with uncertainty, anxiety, exhaustion and frustration, findings that have also been echoed by Harden et al. [3]. According to Sarlo and Holton's survey [38], parents rated KDT as somewhat to very challenging on a scale of 0–10, with a median score of 7. Moreover, 99% of respondents reported experiencing more than one diet-related difficulty. Many of the challenges reported were similar to those found in the theme 'the reality of KD therapy' including a lack of clinical support, a lack of time, family stress, restrictions on social outings, cost, and caregiver stress.

There is a great deal of emphasis on the potential adverse effects of KDT by health professionals, and these are monitored regularly via bloods and imaging. Yet, it was interesting how little emphasis parents placed on these when discussing the challenges associated with KDT. Perhaps parents are reassured by the keto team's close monitoring for adverse effects, and in a sense, they delegate that responsibility to them. In contrast, parents expressed strong concerns about the range of adverse effects associated with ASMs, and some felt their keto team dismissed these concerns. After observing positive results of KDT, parents were often eager to reduce the dose and number of ASMs and were frustrated if their keto team was cautious.

This has implications for how health professionals discuss expectations of KDT with families, and their willingness to attempt to wean an ASM. KDT should be discussed as a partnership with ASMs and not a substitute. This is important in light of the fact that 86% of a cohort of 232 children treated with KDT remained on at least one ASM during and after treatment with KDT [40]. Anecdotally, there is sometimes a misconception amongst health professionals that children must be seizure free before attempting to reduce ASMs. This is not the case [29, 40] and working with families to determine the best timing and order for attempting ASM weaning may strengthen the relationship with their keto team.

While KDT assisted families in managing some of the uncertainties associated with epilepsy, the final theme 'looking to the future' revealed that many parents expressed concern and fear that weaning from KDT would worsen seizure control. It was difficult for parents to 'let go' of this successful treatment. By initiating open conversations and exploring the potential benefits and risks of weaning from KDT, health professionals can assist patients in managing this stress and worry. Few studies have continued to follow patients up post KDT, but those that have suggest that 75–80% of children who are seizure free on KDT will sustain this once KDT is discontinued [41,42]. Similarly, 75% of children who achieved a 50% reduction in seizure frequency maintained these benefits when weaned [42]. These encouraging results should provide reassurance to families considering weaning from KDT.

International recruitment was a strength of this study, with five participants recruited from outside the UK. The use of NVivo software ensured that the stages of analysis were retained, and a clear trail could be mapped through these. There are some limitations to this study. Due to time and budgetary constraints, the study was conducted only in English, limiting international participation to English speakers. The decision to rely on parental proxy reporting of patient experience was made in recognition that many children with cognitive impairments would not be able to participate. Although recruitment strategies varied, our sample included mainly mothers, an issue not unique to our study that perhaps represents the parent who has the most to say on the topic. The majority of children were consuming their KD orally, with the exception of one child who received top-up enteral feeds through a gastrostomy tube. Consequently, the experiences represent those who have managed a KD orally. All children experienced some degree of seizure reduction and nine achieved seizure freedom. Two parents were disappointed with the outcome of KDT, so overall they were arguably a motivated group, keen to share their views on outcomes and experiences of epilepsy and KDT. While there is potential for bias in their responses, their viewpoints are generalisable to the population this study represents; children with epilepsy who trial and continue KDT.

The sampling frame guiding recruitment considered the child's epilepsy diagnosis but omitted developmental status and learning difficulties. Similarly, we omitted to gather demographic data for caregivers. In hindsight, collation of this data may have provided further insights to the study population. The use of ASMs and associated adverse effects was an emotive topic for parents so it would have been beneficial to have more data on the use of ASMs. Firstly, the perceived adverse effects experienced with each ASM and secondly if attempts were made to wean from ASMs and the outcome of this.

5. Conclusion

Our study provides deep and meaningful insights into families' experiences of epilepsy and KDT. Although KDT presents challenges, parents believe the benefits for their children outweigh the difficulties. KDT can provide a problem focussed coping strategy for parents and holistic family centred care from the keto team is essential to support them with this. Parents would welcome improved access to KDT and transition to adult services, access to quality education and support, enhanced variety of KD foods, regular social education and finally consideration of peer mentoring.

The next phase of this programme of research is to develop a bespoke parent reported quality of life measure to address the comprehensive needs of children and young people with complex epilepsy undergoing KDT treatment. The findings from this current study will guide the development of this measure, ensuring it is clinically relevant, family-centred and fit for purpose in ketogenic clinics and research settings.

Data availability statement

The data sets are available from the corresponding author on reasonable request.

Ethics approval statement

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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Declaration of competing interest

The funders had no involvement in the study design, conduct, analysis or write up.

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Appendix 1. COREQ 32 item checklist for qualitative research

Consolidated criteria for Reporting Qualitative research[22]

Item No. and Topic	Guide questions/description	Reported on Page No.
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	2
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	2
3. Occupation	What was their occupation at the time of the study?	2
4. Gender	Was the researcher male or female?	2
5. Experience and training	What experience or training did the researcher have?	2
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	2
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	2
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	2
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	2
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	2
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	2
12. Sample size	How many participants were in the study?	3 and Table 2
13. Non-participation	How many people refused to participate or dropped out? Reasons?	3
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Table 2
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	NA
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	3 and Table 2
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Table 1
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	NA
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	2
20. Field notes	Were field notes made during and/or after the interview or focus group?	2
21. Duration	What was the duration of the inter views or focus group?	2
22. Data saturation	Was data saturation discussed?	NA
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	2
25. Description of the coding tree	Did authors provide a description of the coding tree?	Table 3
26. Derivation of themes	Were themes identified in advance or derived from the data?	2
27. Software	What software, if applicable, was used to manage the data?	2
28. Participant checking	Did participants provide feedback on the findings?	No
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Table 3
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes 3-7
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes Table 3
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes 5-7

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357.

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