A cross-sectional survey of healthcare professionals supporting children and young people with epilepsy and their parents/carers: which topics are raised in clinical consultations and can healthcare professionals provide the support needed?

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ABSTRACT

Background and purpose: Children and young people (CYP) with epilepsy see healthcare professionals (HCPs) for management of their seizures but may require information, advice and support with a range of broader topics. The purpose of the survey was to identify from HCPs, which topics CYP with epilepsy and their parents/carers ask about other than seizure management, and how adequately HCPs feel able to support them with these topics.
Method: A cross-sectional online survey was used to collect data. Adverts which included a link to the survey were shared via social media channels, professional networks and United Kingdom (UK)-based epilepsy networks. Eighty-eight HCPs in the UK (who worked with CYP with epilepsy and their parents/carers) completed the survey. Quantitative data are presented descriptively. Qualitative data (free-text responses) were reflexively thematically analysed.
Results: CYP with epilepsy and their parents/carers were reported to ask HCPs for information, advice and support about a range of topics, most commonly, cognition and mental health. CYP were reported as also frequently asking about aspects of their social life while parents/carers commonly asked about sleep. HCPs varied in how able they felt to adequately support families about these topics, as well as in their views about which resources could be most useful. Having insufficient time and a lack of suitable services and resources to refer to, or draw upon, were key barriers to HCPs being able to support CYP and their families.
Discussion: Findings highlight the broad array of topics CYP with epilepsy and their families are reported as seeking support for. HCPs identified gaps in services and their abilities to meet those needs. There appeared to be a mismatch between the support that families were seeking and the ability of HCPs to meet these needs. Findings have implications for how HCPs could best be supported to deal with topics raised by CYP and families in clinic, highlighting the potential usefulness of informational resources on key topics for HCPs, parents/carers and CYP.

1. Introduction

Epilepsy is a common neurological condition, associated with recurrent seizures that commonly starts in childhood [1,2]. For children and young people (CYP) up to 18 years of age, epilepsy has a population prevalence of around 4.5/1000 [3,4]. More recent prevalence rates for

0–19 year olds suggests prevalence rates for the United Kingdom (UK) are 4.6/1000 [5].

CYP with epilepsy and their parents/carers in the UK are typically cared for by paediatricians, paediatric neurologists and in many cases an epilepsy specialist nurse (ESN) who is described as a 'children's nurse with a defined role and specific qualification and/or training in children's epilepsies' [6] (see S1 for a summary of the pathway of epilepsy diagnosis and care in the UK). A National Institute for Health and Care Excellence (NICE) Quality Statement recommends that CYP with epilepsy should be seen by an ESN who they can contact between scheduled reviews [7]. Recent surveys have identified that just under 80% of CYP in the UK have access to an ESN in children's services [8,9].

Previous research suggested that CYP with epilepsy and their parents perceived that healthcare professionals (HCPs) were solely focused on the 'medical management' of epilepsy [10,11]. Yet recent campaigns such as the 2020 Epilepsy Scotland slogan that '[#]EpilepsyIsMoreThanSeizures' [12] have brought to the forefront the need to look beyond seizures and seizure management. However, nearly 30% of 207 11-to-25 year olds surveyed reported that their HCP did not discuss how epilepsy might have an impact on a range of different aspects of their lives [9]. It is not clear why such a large proportion of CYP were not advised and/or supported on broader issues which were of relevance and importance to them and their families.

The process of undertaking consensus work illustrates that HCPs, CYP with epilepsy and their parents may have different perceptions about the relative importance of outcomes [13]. It has been found that parents and paediatric neurologists have limited agreement about the everyday impact of epilepsy [14] and parents and children have different concerns to each other [15] and are therefore likely to have different questions for their HCPs.

There is evidence of the experiences of CYP and young adults with epilepsy, including the challenges around physical and mental health, personal relationships, daily life and activities, education, their future and negative emotions [16]. Studies have focused on parental concerns around seizures and medication [17] or on what parents' informational needs are about seizure and medication related issues including sudden and unexpected death in epilepsy (SUDEP) [18]. These findings have contributed to highlighting parental need for informational resources [19]. However, parents/carers of CYP with epilepsy hold a myriad of fears and concerns about their child's condition including their mental health, daily life and activities, education, learning and future opportunities [15,20]. How often parents/carers raise these concerns with their child's HCP(s) is not known. Relatedly, it is also unknown how able HCPs feel providing advice and support for these broader topics. However, some work suggests they may not feel equipped; for example, paediatric neurologists have specifically highlighted challenges in effectively supporting mental health [21].

This study was conducted as part of the Changing Agendas on Sleep, Treatment and Learning in Epilepsy (CASTLE) programme of research (https://castlestudy.org.uk/) which seeks to promote changing and enhancing agendas in epilepsy care. In the current study, the aim was to identify HCPs' perspectives on which information/topics CYP with epilepsy and their parents/carers tend to ask about, and how equipped HCPs feel responding to support them around topics beyond seizure management, as well as to identify support which HCPs believed would be beneficial.

2. Materials and method

This study utilised a cross-sectional online survey. The study was conducted and reported in line with the Consensus-Based Checklist for Reporting of Survey Studies (CROSS) [22], Appendix 1.

Questions were created by researchers experienced in epilepsy and research with children and families (GC, LW). Initial draft items were then reviewed by the wider research team and a paediatrician external to the research team as well as members of the CASTLE advisory panel

(see PPIE section). Amendments were made based on feedback, to ensure (i) all key areas of relevance for parents of CYP with epilepsy were addressed and (ii) that items were understandable and appropriately worded. The procedures were approved by Kings College London Research Ethics Committee (MRA-21/22-29681).

Participants were presented with a minimum of 11 items; the total number varied dependent on response options and embedded display logic. Items asking them to report on the most commonly asked about topics were mandatory, all other items were non-mandatory. Where 'other' response options were available, a free-text box was provided and participants were asked to give further clarification. Where relevant, items requested HCPs to select 'all options that applied'. Both quantitative and qualitative data (open text box responses) were generated by the survey. A full copy of the survey (including embedded logic) is in Appendix 2. In brief, the survey included four sections:

1. Topics reported by HCPs as asked about by CYP and HCPs' experiences of supporting them;
2. Topics reported by HCPs as asked about by parents/carers and HCPs' experiences of supporting them;
3. Challenges for HCPs in discussing, supporting and signposting (actively directing patients towards additional advice or support services, organisations or resources) CYP and their parents around topics other than seizures; and
4. HCP profession and details about their role.

In sections one and two, HCPs were asked to rate their perception of the frequency with which various listed topics were asked about (response options: Never, Rarely, Sometimes, Often or Always); then, which topics (maximum 4) were most commonly asked about. For each 'common' topic, HCPs were asked follow-up questions: i. How able they felt to provide advice or signposting (response options: Very able to do this, Partially able to do this, Not able to do this), ii. The specific challenges they faced (response options: Experience, Training/knowledge, Confidence, Time or Other) and iii. What additional support or resources would be most beneficial for them (response options: Training or information/resource for HCPs, Resource for parents/carers, Resource for children and young people, Additional clinical staff or Other).

In section three, participants were provided with an open text box to report challenges in relation to discussing and supporting CYP and their parents around the topics they are asked about. They were also asked whether the Covid-19 pandemic had changed the nature of the topics raised by CYP with epilepsy and their parents (response: Yes, No; and open text box to specify changes).

2.1. Recruitment and participants

Eligibility criterion was being a UK-based HCP who worked with CYP with epilepsy and their parents/carers. An opportunistic sampling approach was adopted, whereby an invitation to participate was shared widely and any healthcare professional (who met inclusion criterion) willing to take part was able to participate. An advert and link to the survey (hosted on Qualtrics [23]) was shared via the main research programme (CASTLE) social media channels, via researchers' professional networks and relevant epilepsy networks such as Organisation of Paediatric Epilepsy Networks in the UK (Open UK). The link took participants directly to the survey participant information sheet where they could provide consent by ticking a checkbox. Consenting participants could then access the survey. The survey was anonymous and did not collect any individual identifying details. The survey was live 20th May 2022 – 9th November 2022. Data were downloaded as an excel spreadsheet before being transferred into analysis software. Because submissions were anonymous and IP addresses were not collected because multiple HCPs could work in the same location and use the same device, it was not possible to take steps to prevent multiple participation of participants. However, submissions were checked for any duplicate

entries (there were none) and the nature of the survey meant that there was no obvious incentive for participants to submit multiple responses.

2.2. Patient and public involvement and engagement (PPIE)

The PPIE is reported in line with the GRIPP-2 short-form [24] as detailed in Table 1. An advisory panel (AP) comprising of three children and young people with epilepsy, ten parents of children with epilepsy and one adult with epilepsy who has lived with epilepsy since childhood was convened for the wider CASTLE research programme to guide all aspects of study development and dissemination. We consulted on two separate occasions with self-selecting members from this AP for this specific study (questionnaire development and interpretation of findings). All members of the AP were compensated for their time and

Table 1
GRIPP 2 short form reporting the PPIE in this study.

Section and Topic	Questionnaire development	Interpretation of findings
Aim of the PPI	To ensure the questionnaire to clinicians addressed issues of importance to parents of children with epilepsy.	To critically consider the findings from the perspective of parents of children with epilepsy who have experienced multiple clinical consultations.
Methods	A lay summary of the proposed study and suggested questions to be asked was emailed to all members of the established advisory panel (AP). The email asked panel members to share their views via email return on the proposed study and questions.	A short presentation of the study findings was made to the AP and questions and thoughts were invited through discussion. The AP met via an online meeting platform, which is an established method of meeting for this group who had wide geographical spread.
Study results	Three parents of children with epilepsy shared their views, suggesting additional questions and demographics to be collected. The parents expressed an interest in the findings and asked for these to be reported back to the AP.	Six parents of children with epilepsy, one adult living with epilepsy since childhood and one young person (aged 17) from the advisory panel reviewed and contributed their thoughts on the study findings. The AP were very interested in the findings and expressed surprise that not all clinicians/HCP felt equipped to deal with sleep and mental health issues when these are such fundamental parts of living with epilepsy. The panel were keen to see if there was a difference in the responses between the clinicians and the epilepsy nurse specialists.
Discussion and conclusions	The additional questions were added to the questionnaire and a revised version circulated to the AP.	The suggested analysis was conducted to explore the differences between consultant and ESN responses to the survey. The outcome of this analysis was fed back to the AP.
Reflections/ critical perspectives	The input from the three parents was valuable in shaping the questionnaire content. There may have been additional items raised if the AP and additional members had been able to meet to discuss the proposed questionnaire.	The views of the parents, adult and young person helped inform analysis. The AP members endorsed that the findings were important and should shape practice. It would have been useful if more of the young people on the AP had been able to attend the planned meeting so their views could have been included.

contributions in line with National Institute of Health Research (NIHR) guidance.

Three parents of CYP with epilepsy from the AP reviewed the initial proposed questionnaire items and provided feedback via email communication. Based on this consultation, amendments to ensure all key areas of relevance for parents of CYP with epilepsy were addressed.

Seven parents and one young person from the AP reviewed and contributed their thoughts and comments on the study findings during an online meeting. Their views shaped some of the analysis conducted; specifically, further analysis was conducted to explore differences between consultant and ESN responses.

2.3. Data analysis

Numerical data were analysed using SPSS v25 [25] and are presented descriptively using frequencies and/or percentages. In some cases where response options were on a 5-point scale these have been reduced to 3-point scales to simplify the presentation and make it easier to identify if topics were or were not often raised by CYP or their parents (e.g. 'always' and 'often' collapsed to represent 'frequently', 'sometimes' remained and 'rarely' and 'never' collapsed to 'infrequently'. Full breakdown of responses for all options are available in supplementary files highlighted in the text. Where there were missing data (many questions were not forced response and/or were nested questions only presented dependent on a previous answer) valid percentages of available data and number of responses are reported.

Text responses were analysed using Braun and Clarke's six-stage reflexive thematic analysis [26,27]. This involved GC reading and rereading textual responses to become familiar with the data. Data were semantically inductively coded. Coding and generating initial themes were undertaken by one researcher (GC). A collaborative approach was then taken with other researchers (LW and BC) to refine themes. Our analysis was reflexive and we considered our positions and existing research relationships and the possible influence on our analysis, see S2 for a summary. A full draft of the findings was reviewed and discussed amongst the wider research team until full agreement was reached that data reflected the meaning expressed in the data.

3. Results

One hundred and fifty-three HCPs started the survey, but only 88 completed and submitted their responses (58 % of those who started after consenting). However, 36 of the 153 (24 %) who consented (by ticking a box on the online questionnaire) did not actually make any attempt to answer any of the survey items.

3.1. Description of the participants

Key details about the sample are presented in Table 2. The sample was predominantly consultants (senior doctors who have completed full medical training and have a clinical specialism) and ESNs (nurses who have a minimum of five years clinical experience in a relevant field who then undertakes specialist epilepsy training) based in England. In order to represent the geographical spread of participants the number of participants in different roles in areas across the UK was divided by the total number of participants in specific roles across the sample. Participants reported a broad range of experience of working with CYP with epilepsy from 1 to 30+ years (0–5 years = 30.7%, 6–10 years = 23.8%, 11–15 years = 16.0%, 16–20 years = 19.3%, 21–25 years = 5.7%, 26 years+ = 4.5%). Participants reported that they worked with CYP across childhood; 0–5 year olds (85%), 6–11 year olds (86.0%) and 12–18 year olds (84.0%).

3.2. Topics reported by HCPs as raised by children and young people

HCPs were asked how frequently CYP with epilepsy asked them for

Table 2
Key details about the sample.

Role	Frequency (%) (N = 88)	Frequency (%) of roles in different geographic locations
Epilepsy Nurse specialist (ESN)	35 (39.8)	
Consultant	36 (40.9)	
Associate specialist	1 (1.1)	
Trainee doctor/fellow	4 (4.5)	
Other*	12 (13.6)	
Department (n=91)˜		
General paediatrics	43 (47.2)	
Community paediatrics	17 (18.7)	
Paediatric neurology	23 (25.3)	
Other^	8 (8.8)	
Location		
England	78 (88.6)	ESN = 31 (88.6), Consultant = 32 (88.9), all other roles = 15 (88.2)
Scotland	5 (5.7)	ESN = 2 (5.7), Consultant = 2 (5.6), all other roles = 1 (5.9)
Wales	2 (2.3)	ESN = 1 (2.8), Consultant = 1 (2.8)
Republic of Ireland	2 (2.3)	ESN = 1 (2.8), Consultant = 1 (2.8)
Northern Ireland	1 (1.1)	ESN = 0 (0.0), Consultant = 0 (0.0), all other roles = 1 (5.9)
England (n = 78, region)		
North East	6 (7.7)	ESN = 3 (9.7), Consultant = 3 (9.4), all other roles = 0 (0,0)
North West	16 (20.5)	ESN = 4 (12.9), Consultant = 7 (21.9), all other roles = 5 (33.3)
East Midlands	3 (3.8)	ESN = 0 (0.0), Consultant = 2 (6.3), all other roles = 1 (6.7)
West Midlands	1 (1.3)	ESN = 0 (0.0), Consultant = 0 (0.0), all other roles = 1 (6.7)
East of England	6 (7.7)	ESN = 1 (3.2), Consultant = 2 (6.3), all other roles = 3 (20)
London	26 (33.3)	ESN = 12 (38.7), Consultant = 19 (31.3), all other roles = 4 (26.6)
South East	19 (24.4)	ESN = 10 (32.3), Consultant = 8 (22.2), all other roles = 1 (6.7)
South West	1 (1.3)	ESN = 1 (3.2), Consultant = 0 (0.0), all other roles = 0 (0.0)

* psychologist (n=5), dietician (n=2), nurse (n=2), rehabilitation unit manager (n=1), support worker (n=1), clinical physiologist (n=1).
˜ n=3 participants reported working in 2 different departments simultaneously.
^ Acute hospital trust (n=1), community children's nursing (n=1), neuropsychology (n=3), paediatric neurodisability (n=2), rehabilitation unit (n=1).

information or advice about 11 key topic areas. Social life, cognition, mental health and sleep were the most commonly reported topics. Their future and physical health were also topics HCPs reported as being frequently consulted about. See Table 3 for details and S3 for full breakdown.

HCPs were asked to select which were the most common topic areas (maximum of 4) that CYP with epilepsy asked them about in relation to their epilepsy (beyond seizure management). The most common five were social life (18.4%), mental health (17.8%), cognition (17.5%), their future (13.6%) and sleep (12.0%). See S4 for full breakdown of frequency and proportion different topics were reported by HCPs as being most commonly asked about by CYP.

For the topics that HCPs reported as being most frequently raised by CYP they were asked whether they felt able to provide advice or signposting about these topics to CYP with epilepsy. Although not widely asked about topics (S4), it appeared HCPs felt most comfortable supporting CYP around the topics of SUDEP, physical health and transitioning to adult services.

Of the commonly asked about topics (i.e. social life, mental health, cognition, their future and sleep) HCPs were most confident advising about social life (see Table 4, S5 includes additional details about responses relating to 'other' topics). Paradoxically, many HCPs reported

Table 3
Frequency (%) of responses about how frequently CYP with epilepsy ask for information or advice on key topic areas.

	N = 88 (unless specified)		
	Frequently	Sometimes	Infrequently
Mental Health*	48 (55.2)	25 (28.7)	14 (16.1)
Sleep^	44 (51.2)	20 (23.3)	22 (25.6)
Social life^	49 (57.0)	29 (33.7)	8 (9.3)
Physical health*	25 (28.7)	42 (48.3)	20 (23.0)
Cognition	49 (55.7)	31 (35.2)	8 (9.1)
Puberty*	13 (14.9)	40 (46.0)	34 (39.1)
Their future	30 (34.1)	45 (51.1)	13 (14.8)
Impact on family/family life	23 (26.1)	32 (36.4)	33 (37.5)
Transition to adult services˜	22 (25.0)	36 (42.4)	27 (31.8)
Seizure monitoring devices*	26 (29.9)	27 (31.0)	34 (39.1)
SUDEP	10 (11.4)	15 (17.0)	63 (71.6)
Other#	12 (21.8)	7 (12.7)	36 (65.5)

* n = 87 responses.
^ n=86 responses.
˜ n=85 responses.
Other (n=56 and where specified other topic areas were reported as): medication (n=11), prognosis (n=2), sporting activity (n=1), driving (n=1) behaviour (n=1), respite (n=1), CBD (n=1), school training (n=1), appointment related (n=1).

Table 4
Frequency (%) of how able healthcare professionals felt to provide support around the most common topics they were asked about by CYP with epilepsy.

	Yes	Partially	No	Total number of individuals who reported topic was a key area CYP asked them about and also reported how able they felt to support
Mental Health	28 (48.3)	29 (50.0)	1 (1.1)	58
Sleep	20 (50.0)	19 (47.5)	1 (1.1)	40
Social life	39 (63.9)	21 (34.4)	1 (1.6)	61
Physical health	8 (72.7)	3 (27.3)	0(0)	11
Cognition	30 (52.6)	26 (45.6)	1 (1.8)	57
Puberty	9 (60)	6 (40.0)	0(0)	15
Their future	26 (57.8)	18 (40.0)	1 (2.2)	45
Impact on family/family life	5 (55.6)	4 (44.4)	0(0)	9
Transition to adult services	7 (63.6)	3 (27.3)	1 (9.1)	11
Seizure monitoring devices	9 (60.0)	5 (33.3)	1 (6.7)	15
SUDEP	2 (100)	0(0)	0(0)	2

HCPs were asked this question as a follow up after selecting a maximum of four key areas that they reported CYP asked them about. Therefore, each row represents the total number of HCPs who selected that topic as one of their 'top four' and provided a response regarding how able they felt about providing support. Given that the 'other' option was selected by many participants without specification of what the specific topic and other categorised topics representing very small numbers the 'other' category is omitted from this table.

feeling only partially being able to support around the two most asked about topics of mental health and sleep, as well as cognition and the CYP's future. Given the potential differences in consultant and ESN roles and experiences in dealing with different topics, a comparison of their perceived ability to support CYP was undertaken. This information is presented in S5 and data suggests there was little difference between the groups.

HCPs were asked what the particular challenges were for them in being able to provide advice or signposting about the specific topics to CYP with epilepsy. Lack of time was the most commonly reported obstacle reported across the different topic areas. Insufficient training or knowledge of the area was widely reported for many topic areas and, to a lesser extent, lack of practical experience was a challenge for some key areas (see Table 5, S6 includes additional detail about responses relating to 'other' topics). In addition to the challenges noted, some HCPs selected 'other' but did not expand upon what the challenge was. However, the qualitative results presented later delineate the challenges they experienced in supporting CYP around various topics. S7 provides a comparison of the reasons Consultants and ESNs reported challenges in supporting CYP with epilepsy. There appears to be little difference in the reasons stated by the two groups of HCPs.

Finally, HCPs were asked what additional support or resources they thought could be most beneficial to them in providing advice or signposting around the topic areas to CYP with epilepsy (see Table 6 and S6 for further details about responses relating to 'other' topics). For many topic areas (social life, mental health, cognition, their future and sleep) HCPs felt a resource for parents/carers and for CYP with epilepsy would be most useful. HCPs also felt they themselves could benefit from training, information or resources to support their practice in these areas.

3.3. Topics reported by HCPs as raised by parents/carers of children and young people with epilepsy

HCPs were asked how frequently parents or carers asked them for information or advice about 11 key topic areas. Behaviour, cognition, sleep and mental health were the most frequently reported topics. HCPs reported that their child's future, social life, impact on family and physical health were also commonly asked about topics. See Table 7 for details and S8 for full breakdown.

HCPs were asked to select which were the most common topic areas (maximum of 4) that parents/carers asked about in relation to their CYP with epilepsy (beyond seizure management). The most common five were their child's cognition (18.3%), behaviour (17.8%), mental health (16.3%), sleep (15.5%) and impact on family/family life (6.9%). See S9 for full breakdown of the frequency and proportion different topics were reported as being most commonly asked about by parents/carers.

Next, HCPs reported how able they felt to provide advice or

Table 5
Reasons healthcare professionals report experiencing challenges in supporting CYP with epilepsy around topic areas (frequency).

	Experience	Training/ knowledge	Confidence	Time	Other
Mental Health	11	25	5	34	20
Sleep	7	15	1	16	5
Social life	6	19	6	35	6
Physical health	1	3	2	7	0
Cognition	9	21	3	25	7
Puberty	3	5	2	8	1
Their future	5	18	4	25	4
Impact on family/family life	0	2	2	4	0
Transition to adult services	1	2	0	4	2
Seizure monitoring devices	0	8	0	6	2
SUDEP	1	0	1	1	0

HCPs were asked this question as a follow up after selecting a maximum of four key areas that they reported CYP asked them about. Therefore, each row represents the total number of HCPs who selected that topic as one of their 'top four' and provided a response regarding challenges (selecting all that applied) they experienced in supporting CYP with epilepsy.

Table 6
Resources that healthcare professionals report would be most useful to help them to best support children and young people across key topic areas (frequency of HCPs selecting this resource).

	Training or information/ resource for you	Resource for parent/ carer	Resource for child/ young person	Additional clinical staff
Mental Health	34	43	43	43
Sleep	20	33	28	14
Social life	28	44	49	28
Physical health	7	7	7	6
Cognition	28	43	42	24
Puberty	8	11	14	4
Their future	22	29	31	18
Impact on family/ family life	5	6	5	5
Transition to adult services	3	8	7	3
Seizure monitoring devices	10	11	10	2
SUDEP	2	2	2	1

HCPs were asked this question as a follow up after selecting a maximum of four key areas that they reported CYP with epilepsy asked them about. Therefore, each row represents the total number of HCPs who selected that topic as one of their 'top four' and provided a response regarding what would be most useful to help them (selecting all that applied) to provide support to CYP with epilepsy.

Table 7
Frequency (%) of responses about how frequently HCPs report parents/carers asking for information or advice on key topic areas.

	N=88 (unless specified)		
	Frequently	Sometimes	Infrequently
Mental Health	72 (81.8)	13 (14.8)	3 (3.4)
Sleep	74 (84.1)	11 (12.5)	3 (3.4)
Social life	58 (65.9)	22 (25.0)	8 (9.1)
Physical health	46 (52.3)	34 (38.6)	8 (9.1)
Cognition	80 (90.9)	6 (6.8)	2 (2.3)
Behaviour*	81 (93.1)	4 (4.6)	2 (2.3)
Puberty*	18 (20.7)	37 (42.5)	32 (36.4)
Their child's future	46 (52.3)	35 (39.8)	7 (8.0)
Impact on family/family life	56 (63.6)	24 (27.3)	8 (9.1)
Transition to adult services*	34 (38.6)	41 (47.1)	12 (13.8)
Seizure monitoring devices*	44 (50.6)	29 (33.3)	14 (16.1)
SUDEP	12 (13.6)	31 (35.2)	45 (51.1)
Other˜ (n = 49)	16 (32.7)	2 (4.1)	31 (63.3)

* n=87 responses, all other responses n=88.
˜ Other (n=49 and where specified other topic areas were reported as): medication (n=9), care plans (n=3), school training/training (n=2), diet (n=1), siblings (n=1) prognosis (n=1), neurodisability (n=1), transport (n=1), CBD (n=1).

signposting around the most frequently asked about topics. HCPs reported that they felt most comfortable supporting parents or carers around the topics of SUDEP and puberty, although these were not topics that were most often raised by parents/carers (see Table 8, S10 includes additional details about responses relating to 'other' topics).

Of the commonly reported topics (i.e cognition, behaviour, mental health, sleep and impact on family/family life) many HCPs felt only partially able to provide support around the topics of cognition, behaviour, mental health and sleep. A comparison of how able Consultants and ESNs felt in providing support is reported in S11 and suggests little difference between the two groups.

Lack of time and insufficient training or knowledge were again the most commonly reported challenges HCPs faced in being able to provide advice or signposting about the specific topics to parents or carers. These

Table 8

Frequency (%) of how able healthcare professionals felt to provide support around the most common topics they were asked about by parents of CYP with epilepsy.

	Yes	Partially	No	Total number of HCPs who reported topic was a key area parents/carers asked them about and also reported how able they felt to support
Mental Health	20 (35.1)	36 (63.2)	1 (1.8)	57
Sleep	28 (51.9)	25 (46.3)	1 (1.9)	54
Social life	8 (40.0)	12 (60.0)	0(0)	20
Physical health	8 (50.0)	7 (43.8)	1 (6.3)	16
Cognition	32 (50.0)	30 (46.9)	2 (3.1)	64
Behaviour	23 (37.1)	36 (58.1)	3 (4.8)	62
Puberty	2 (66.7)	1 (33.3)	0(0)	3
Their child's future	4 (26.7)	11 (73.3)	0(0)	15
Impact on family/family life	13 (54.2)	11 (45.8)	0(0)	24
Transition to adult services	5 (55.6)	3 (33.3)	1 (11.1)	9
Seizure monitoring devices	11 (50.0)	10 (45.5)	1 (4.5)	22
SUDEP	3 (100)	0(0)	0(0)	3

HCPs were asked this question as a follow up after selecting a maximum of four key areas that they reported parents/carers asked them about. Therefore, each row represents the total number of HCPs who selected that topic as one of their 'top four' and provided a response regarding how able they felt about providing support. Given that the 'other' option was selected by many participants without specification of what the specific topic and other categorised topics representing very small numbers the 'other' category is omitted from this table.

were barriers for many topic areas, particularly mental health,

Table 9

Reasons healthcare professionals report experiencing challenges in supporting parents/carers of CYP with epilepsy around topic areas (frequency).

	Experience	Training/ knowledge	Confidence	Time	Other
Mental Health	18	32	7	29	15
Sleep	8	21	1	29	9
Social life	6	11	1	10	2
Physical health	3	8	2	9	1
Cognition	16	28	7	29	10
Behaviour	12	30	8	35	11
Puberty	1	2	0	2	0
Their child's future	5	9	1	9	0
Impact on family/family life	5	7	3	14	5
Transition to adult services	1	1	0	4	1
Seizure monitoring devices	2	10	1	8	5
SUDEP	0	1	0	2	0

HCPs were asked this question as a follow up after selecting a maximum of four key areas that they reported parents/carers asked them about. Therefore, each row represents the total number of HCPs who selected that topic as one of their 'top four' and provided a response regarding challenges (selecting all that applied) they experienced in supporting parents/carers.

behaviour, cognition and sleep (see Table 9, S7 for additional details about responses relating to 'other' topics). Lack of practical experience was also a challenge for some key areas (mental health, cognition and behaviour). Some HCPs selected 'other' but did not expand upon what this challenge was. However, the qualitative results presented in the paper below explore the challenges they experienced in supporting CYP around various topics. S12 provides a comparison of the reasons Consultants and ESNs reported as challenges to them supporting parents/carers and there appeared to be little difference between the two groups of HCPs.

The additional support or resources that HCPs thought could be most beneficial to them in providing advice or signposting around the topic areas to parents/carers are shown in Table 10 (S7 includes additional details about responses relating to 'other' topics). For topic areas commonly asked about by parents/carers (i.e. cognition, behaviour, sleep, mental health) HCPs felt a resource for parents/carers and for CYP with epilepsy, as well as training, and information or resources for themselves could be beneficial. HCPs also felt there was a need for additional clinical staff to assist them in providing information or support on topics of importance.

Given the time when the data were collected (i.e. post-pandemic, May–November 2022) we specifically explored their views about whether the Covid-19 pandemic had changed the questions or topics that CYP with epilepsy and their parents/carers ask about. Nearly two-thirds (64.8%) reported no.

3.4. Qualitative results

HCPs were asked open-ended questions about their biggest challenges in discussing topics (other than seizures and seizure control) with CYP with epilepsy and their parents/carers. Four themes) and associated subthemes were identified (Fig. 1):

- Having and giving enough time
- Accessing and finding appropriates health service resources or services (sub-themes: need for more Epilepsy Nurse Specialists, Lack of

Table 10

The frequency of resources that healthcare professionals report would be most useful to help them best support parents/carers across key topic areas.

	Training/ information/ resource for you	Resource for parent/ carer	Resource for child/young person	Additional clinical staff
Mental Health	30	43	35	45
Sleep	26	44	37	21
Social life	10	19	18	10
Physical health	9	13	9	7
Cognition	27	51	42	30
Behaviour	28	49	34	36
Puberty	2	3	3	1
Their child's future	9	13	12	4
Impact on family/ family life	11	20	15	12
Transition to adult services	3	7	4	2
Seizure monitoring devices	14	15	12	7
SUDEP	3	3	3	0

HCPs were asked this question as a follow up after selecting a maximum of four key areas that they reported parents/carers asked them about. Therefore, each row represents the total number of HCPs who selected that topic as one of their 'top four' and provided a response selecting all that applied) regarding what would be most useful to help them provide support to parents/carers.

Fig. 1. Overview of main themes.

referral pathways for broad psychological support, Not enough mental health support for children and young people);

- Communication, providing reassurance and broaching sensitive subjects; and
- Reducing social isolation and increasing access to community-based support

Each theme (and any associated subthemes) are presented along with supporting quotations. Each quote is followed by the participant number and their role (signified by Cons = Consultant, ESN = Nurse Specialist Nurse, Trainee = Trainee doctor/fellow, Associate specialist = Assoc, Other = other) to provide context to the responses.

3.4.1. Having and giving enough time

HCPs commonly reported on the time pressures they faced within clinic consultations acknowledging 'insufficient time allocation for consultations' (71-Cons) meaning there was limited 'time to talk about the topics' (P63-Cons). They reported on how these time constraints influenced what they could achieve:

> There just isn't enough time during a clinic appointment without the risk of overloading patients and carers with too much information (P54-Trainee).

Time to offer advice and support was in short supply for various reasons and often resulted in not being able to provide 'anything except minimal support and one-off advice' (P21-ESN). Reasons for this included not having the 'time to find and provide the resources [and] lack of easy to find resources' (P63-Cons) and being 'a single practitioner covering a large area and a caseload of 500' (P21-ESN). Others noted that the complexity of their caseloads made time constraints more problematic:

> many of the patients have comorbidities especially neurodisability/ palliative care needs which are very time consuming in a 30 min clinic appointment to address and this seems to be overlooked/not measured by Epilepsy12 (P60-Cons).

Some HCPs realised that time constraints impacted not only clinic consultations but were also evident as there were insufficient staffing levels across services 'to be able to provide the support' (P75-ESN).

3.4.2. Accessing and finding appropriate health service resources or services

Common challenges for supporting CYP with epilepsy and their families was reported to be the general '[un]availability of appropriate services to link in with' (P14-ESN) and 'unclear referral pathways for support' (P20-Trainee). These were widespread issues affecting referral into core services for assessment, intervention, and support. Those services that did exist were often extremely limited or stretched:

> We have practically NO community paediatric service at our hospital (P27-Cons).

Challenges included parents experiencing problems with 'waiting times/referral criteria, getting GP appointments/prescriptions, waiting times to see local paediatrician [and] have support from them' (P81-ESN). Additional challenges were posed when HCPs were asked by CYP and parents/carers for support for issues beyond seizure management:

> Sometimes finding the correct support or signposting to the right professionals can be a challenge (P7-ESN).

Scarce resources and services in primary and secondary care resulted in tertiary service HCPs having to provide help and support with broader issues which they would not typically or HCPs had to find alternate ways to support CYP and their parents and this involved 'looking at the voluntary/charity sector and this can be time consuming' (P67-ESN).

Three subthemes represented specific challenges related to the identification and access of appropriate resources or services.

3.4.2.1. The need for more epilepsy specialist nurses (ESNs). A specific challenge related to 'limited availability of' (P44-Cons) or 'reliable access to' (P54-Trainee) an ESN. Some clinicians noted that ESNs were best placed to support many of the topics raised by CYP with epilepsy and their parents, particularly with issues outside of seizure management as they are:

> …invaluable in providing quality information and support - we just need more epilepsy nurse specialists to provide a higher quality of service (P79-Cons).

3.4.2.2. Lack of referral pathways for broad psychological support.. There were also challenges for HCPs related to wider psychological services such as 'no clinical psychology locally' (P18-ESN) and 'lack of

educational psychology for children with milder learning difficulties not in a specialist school setting' (P44-Cons). In addition, a lack of or confusing referral routes for psychological 'input' (P82-ESN) and 'support' (P28-ESN) was pervasive. Delays in 'timely support after referral, for example to clinical psychology or school educational support' (P20-Trainee) were noted and this was linked to 'lack of adequate staffing' (P19-Cons).

Part of the challenge related to the lack of epilepsy-specific services, 'clinical psychologist support for epilepsy is very limited' (P57-Cons). Further, it was clear that the complexity of many CYP's clinical condition and comorbidities meant that they did not meet psychological support services criteria 'psychology reject 80% of referrals in our area' (P60-Cons) as "learning difficulties/behaviour problems/autism/ADHD etc" are not deemed relevant (P60-Cons).

3.4.2.3. Not enough mental health support for children and young people. Although all services appeared to have limited service provision, a specific area widely highlighted as especially lacking, was 'getting mental health support for our patients' (P47-ESN).

Getting CYP appropriately referred to and seen in a timely manner by mental health support services was widely problematic, often due to the lack of 'trained local mental health carers' (P4-Cons) and 'relevant professionals, usually CAMHS [Child and Adolescent Mental Health Service], and obscene waiting lists if the child gets accepted' (P11-Cons).

Gaps were also reported in the availability of both good quality 'mental health services/therapy support available in-house' (P52-ESN) or services 'we can reliably refer or signpost to' (P34-Cons). Even when services existed, some HCPs noted that referral routes for mental health issues lacked clarity as 'referral pathways [are] confused' (P53-Cons).

HCPs acknowledged additional challenges arose as some CYP presented with complex histories, difficulties and comorbidities which affected 'cognition, learning and behaviour, depression and anxiety' (P27-Cons). Where services did exist, there was a sense of frustration that 'often CAMHS won't help' (P68-Cons) if the CYP was referred with a behavioural issue. One clinician noted:

> Although we feel qualified and experienced in recognising such problems and can advise on them we do not have the onwards referral routes with which to take diagnosis and management forward (P27-Cons).

Further, HCPs noted that compared to CYP with other chronic conditions, CYP with epilepsy had poorer support for their mental health as they had:

> No support from the mental health team in clinics, they should all see a member of the mental health team like clinical psychologist like other services like diabetes (P37-ESN).

3.4.3. Communication, providing reassurance and broaching sensitive subjects
HCPs noted that communication in general, but especially in certain circumstances, was challenging. This could be compounded when the language skills and/or cognitive capabilities of parents made effective communication difficult:

> Sometimes language barriers can make communication difficult. Some parent/carers have learning difficulties or disabilities which impact understanding (P59-ESN).

Parental knowledge, understanding and beliefs about diagnosis and treatment paths also posed a challenge for some HCPs as these could influence the 'assessment and rehabilitation process' (P64-Other-Rehabilitation Unit Manager). Knowing how to 'broach the subjects' (P61-

Assoc) with CYP and parents was noted to be challenging and was heightened by 'the complexity and unpredictability of epilepsy' (P82-ESN). Offering reassurance could be made even more difficult if the consultation was with 'very demanding and verbal aggressive parents' (P56-ESN).

HCPs found it difficult to navigate when faced with communicating about an area where the evidence base was poor or where they noted a 'lack of evidence-based information/training on the management of various epilepsy related factors' (P58-ESN). They noted that sometimes there is 'not a huge amount of evidence to support discussions' (P41-Other-dietitian). This was particularly problematic for some specific topic areas of significance to parents such as a 'monitoring alarms' (P82-ESN).

The lack of good quality resources and information for 'parents/carers or support workers' (P42-Other-Support worker) was noted as was a lack of resources to facilitate communication. This was seen to be particularly problematic for CYP and for those in discrete clinical groups, such as: 'children and young people who have learning difficulties/learning disability (and also for their parents)' (P30-Cons).

3.4.4. Reducing social isolation and increasing access to community-based support
Social isolation was a key concern, which caused challenges for the family and indirectly the HCPs. Further to a lack of formal support services, HCPs reported that there was currently a 'lack of community support' (P28-ESN), which in turn affected HCPs because it increased the demand for families' support needs to be met by healthcare services. They noted improvements could be achieved through increased 'access to social care support to enable access to support and activities within the community' (P24-Other-Psychologist).

Increasing community-based support was also proposed as a way to encourage peer support and reduce social isolation through therapeutic groups and social events. But it was acknowledged that there was 'little available in the way of mechanisms for them to socialise and meet' (P10-Other-Psychologist) and that:

> More resource/funding for group/social interventions would be beneficial (P70-Other-Psychologist).

4. Discussion

Results of this study highlight the broad array of non-seizure-related topics which CYP with epilepsy and their families are reported as seeking support with, from clinicians involved with their epilepsy care. There was some overlap between clinicians' reports of the most common topics CYP and parents asked about but also some concerns which were specific to each group. Notably, both CYP and parents were reported as having epilepsy-related concerns beyond seizures for which they regularly sought help yet the extent to which clinicians felt able to support families with these topics varied considerably. Some of the most commonly asked about-topics were those for which they felt less able to offer support. Reasons for this were multiple but included insufficient time during clinic appointments, lack of training and/or expertise in these areas, communication challenges and limitations in existing services to provide more integrated care.

The CYP's mental health, cognition and sleep were topics reported as frequently raised by both CYP and their parents. Other commonly raised topics were specific either to CYP (their future and their social life) or their parents (the CYP's behaviour), likely indicating that the salience of different areas of functioning may differ for CYP and their parents. Qualitative work with parents and CYP with epilepsy identified similar patterns, with areas of shared concern around the child's future and psychological wellbeing but also some differences, with young people reported as being particularly concerned about their relationships with peers [15]. Understanding of the (mis)alignment between the topics of interest for CYP and their parents and the clinicians' abilities to support

around these areas, remains limited. However, it is clearly critical to understand both parents' and CYP's perspectives, when trying to understand and provide support for families' needs.

There were some particular topics, mainly medically focused, for which more clinicians reported feeling comfortable offering support (i.e. the topics of SUDEP, physical health, puberty, transitioning to adult services, seizure monitoring devices and the CYPs' social life). However, these were not reported to be the most commonly asked about topics, either by parents or CYP, as most commonly reported concerns related to the CYP's broader psychosocial functioning. It is perhaps surprising that only a small proportion CYP and their parents are asking about SUDEP in clinic. Perhaps one explanation is that healthcare professionals (especially consultants and ESNs) should be routinely raising the topic of SUDEP in clinical consultations and so there was less of a need for CYP or parents themselves to raise the topic. It was interesting to note that clinicians reported feeling more comfortable supporting questions on CYPs' social life when these were raised by the CYP rather than their parents, although the reasons for this are not clear. Perhaps unsurprisingly, clinicians exhibited what could be considered 'clinical uncertainty' [28] in that they felt better able to offer support on topics which appeared to be those more directly related to their area of clinical speciality (i.e. epilepsy) and less able to help on topics less familiar to them. However, on review of our results, the advisory panel to the current study were surprised that not all clinicians/HCPs felt equipped to deal with sleep and mental health when these were seen as such fundamental aspects of living with epilepsy.

Some clinicians who work with CYP with epilepsy may have additional training needs (and a need for greater access to appropriate referral pathways) to be capable and confident addressing the very broad range of relevant issues beyond medical management, such as mental health [29]. However, the difficulties associated with offering support for some topics were not all obviously addressed by additional knowledge/training for clinicians. In some cases, reported challenges related to the uncertain nature of epilepsy in childhood, where some aspects of the child's condition, management and future may at times be, or at least feel, ambiguous for CYP, parents and clinicians [30,31]. Other, often long-standing, reported challenge included those which have been noted as widespread problems, not unique to epilepsy clinicians/services (i.e. a lack of time both during clinic appointments and because of pressures on their service) [32], a lack of access to appropriate services or staff/issues around referral pathways, including for mental health support [33] and communication challenges, such as language barriers [34].

Despite these challenges, the importance of supporting CYP with epilepsy have been nationally acknowledged in the recent NHS Core20PLUS5 approach to reducing health inequalities for CYP, which identified epilepsy as a clinical area of focus [35]. The Royal College of Paediatrics and Child Health [36] also made the case to NHS England for the need for investment in services for CYP with epilepsy, specifically to try and address the types of topics which were highlighted by clinicians in the current survey. There is clearly a recognition of the need for more comprehensive and integrated care for CYP with epilepsy, including the (often inter-related) areas of mental health, cognition and sleep, as recommended by NICE [37,38] and in The Epilepsy 12 report [8]. Unfortunately, this is often lacking: for example, in November 2020, nearly 40% of the England and Wales Health Boards and Trusts audited as part of the Epilepsy 12 clinical audit did not have agreed mental health referral pathways CYP with epilepsy [8]. The importance of holistic and integrated care for CYP with ongoing conditions, including those with epilepsy, was emphasised by Satherley et al., [39] who reported that families valued co-ordination between health, social and education services for children and also identified that nurses able to work across those organisational boundaries, such as ESNs, could offer vital support which could mitigate some of the challenges associated with poorly funded and fragmented services. Such service improvements could be expected to have benefits not only for the CYP, their families and the

clinicians involved with their care but also potential wider economic benefits if some co-existing difficulties could be treated and/or prevented from becoming longstanding.

NICE [37] guidelines provide clear and explicit guidance on who should be supporting children and young people with epilepsy and their parents, including the availability of specialist support services such as access to mental health services. The current results suggest that these are not always consistently achieved (e.g. access to ESNs and mental health referral pathways available), with the result that healthcare professionals support and referral pathways are highly variable with potential implications for where and from whom CYP with epilepsy and their parents receive advice and support. Of course, addressing service-related issues requires reorganisation and funding, and therefore may be difficult to quickly resolve, as well as being expensive. Clinicians participating in the current survey indicated some alternative or additional approaches which they thought could also be useful (for parents, CYP and clinicians), including the availability of informational resources around key topics and fostering the development of community-based support. After reviewing these results, the advisory panel to the current study were surprised by clinicians' views that resources designed for parents and CYP were more important than training for themselves, as this could be interpreted as diverting responsibility away from the clinician/HCP to deliver holistic care and onto families to find their own solutions. Of course, an alternative interpretation is that clinicians are being pragmatic, believing that such approaches are more easily and quickly realised than service-related changes.

Indeed, various information resources are already available from a number of charities (e.g. Epilepsy Action, Epilepsy Society, Young Epilepsy) and organisations (e.g. International League Against Epilepsy) and some services have developed their own resources [8]. However, the current work suggests the available resources may not be widely used and/or do not fully meet the needs of CYP and their parents. Additionally, and/or alternatively, more appropriate and effective signposting is required. Future qualitative work involving clinicians, parents and CYP of different ages could help identify (from these different user group perspectives) the precise topics and types of content (i.e. information or signposting) which would be helpful for them as well as the preferred format for delivering any relevant content. Of course, the development of guidance needs to be based on available evidence and clinicians in the current survey also highlighted the need for more research to underpin and inform the care of CYP with epilepsy; for example, limitations in the existing evidence base around the use of seizure monitoring alarms makes it difficult to advise families appropriately [40].

Communication challenges between patient and healthcare professional around the topics discussed in clinical consultations and the differing perspectives of the value of discussions around broader impact of epilepsy on patients' lives has been identified in the adult literature [41]. In the current study, some of the challenges highlighted by clinicians in supporting CYP and their parents related to the difficulties of communicating sensitive and/or complex information, especially with CYP and parents who had learning disabilities or language barriers. As effective communication is vital for patient-centred care, accessible advice for these specific groups is paramount and could include the use of translated and/or adapted written materials. For example, 'Easy Read' health information is adapted for use with people with intellectual disabilities, using short, jargon-free sentences and supported with visual aids [42,43]. Extending coverage to matters raised by CYP with epilepsy and their parents would clearly be helpful. In addition to acting as a resource for patients and their families such booklets have been noted to be helpful for guiding and structuring inexperienced clinicians' approaches to any conversation with families [44]. The results of the current study suggest that many clinicians would also welcome tips about how to effectively communicate with people with intellectual disabilities [45,46].

Beyond the clinic, many clinicians also suggested that increasing peer and social support would be an additional resource for families and

helpful for combating social isolation and increasing engagement with harder to reach groups. The desire for peer support (for CYP with epilepsy and parents) and the value of the ability to share with and receive information from appropriate peers has been identified by others (e.g. [47]) as have the links between peer support, quality of life and mental health in epilepsy [48,49,50].

This study has limitations which should be considered when interpreting the results. Firstly, response bias; although responses were received from clinicians based across the UK, most of the respondents were based in England, and the majority in London or the South-East. Whether the findings are generalisable to the whole of UK or internationally is not known. Some of the challenges identified (e.g. lack of services to refer patients to) could be more extreme in more remote or rural areas or reflect factors related to individual practise or settings. The impact of patient and family demographics (such as ethnicity, race and/or socioeconomic status) are also important areas to consider in future work. Secondly, whilst participants included representatives of both ESNs and consultants working in a range of settings (e.g. general paediatrics, community paediatrics and neurology), it is not clear how representative the sample is of all HCPs working with CYP with epilepsy and their parents – although it is maybe worth noting that, perhaps surprisingly, there appeared to be little difference between the consultants and ESNs in terms of their reported ability to offer support and the reasons for any challenges in doing so. Thirdly, the qualitative analysis was conducted on data obtained via open-ended questionnaire responses, which meant that it was not possible to follow-up on any points which were raised. It would be useful for future work in this area to use interviews so that responses could be appropriately explored in more detail. Lastly, this work presents clinicians' views about the topics which are raised by CYP with epilepsy and their families. This perspective is valuable, but future surveys (or interviews) with CYP with epilepsy and their parents as respondents would be useful, especially given that there can be differences between the views of the different groups in terms of what is 'important' or a worry (as evidenced in the current findings, but also the work of others [14,15]) and because the child's voice is too often absent or under-represented in research addressing epilepsy in [51]. Triangulation of data would help to better identify all parties' needs and therefore potential resources/solutions to best meet these.

5. Conclusion

In conclusion, despite increasing recognition of the widespread concerns and care needs of CYP with epilepsy and their parents, the results of this study suggest that many existing services may not always be equipped to meet their needs. Clinicians identify that their ability to support CYP with epilepsy and their parents with the full range of their concerns is often compromised. A lack of time in clinic, gaps in provision by NHS and non-statutory services, and lack of training all contributed to the challenge of offering the required integrated care. This paper is not written with the intention of being critical of the stretched services and dedicated clinicians but rather, to contribute to the evidence which suggests that services offering care for CYP with epilepsy need to be equipped to address both their medical and psychosocial challenges. In addition, we hope to bring attention to the potential variety of resources and approaches which could all contribute to meeting that need. Informational resources on key topics for clinicians, parents and CYP and the development of more community-based support could offer some possibility to mitigate, although not overcome, some of the existing difficulties. As a first step, encouraging and supporting broader discussion between HCPs and families, of the topics which matter to CYP with epilepsy and their parents, would be useful and perhaps could help to change agendas in epilepsy care.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Supplementary material

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