

**Mental Health Information Needs in Epilepsy – Insight From Young People
With Epilepsy and Parents**

Sasha Barton

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Lay Summary

Epilepsy is a neurological condition, characterised by seizures, that impacts many young people and adults around the world.

Systematic Review

Introduction

Young People with Epilepsy (YPWE) need information about epilepsy. Information sharing has many benefits and clinical guidance suggests that timely information should be shared with patients. However, this does not always happen. A previous systematic review highlighted that YPWE had gaps in their knowledge. However, this review was conducted over a decade ago. An updated review of knowledge levels amongst YPWE was needed.

Nurses play an important role in sharing information for people with epilepsy worldwide. Evidence has also suggested that there are gaps in nurses' knowledge about epilepsy. However, there were no published reviews that investigated this.

The aim of this review was to understand epilepsy-related knowledge levels, and the factors linked to knowledge, amongst YPWE and nurses.

Methods

A systematic literature search was carried out to find research that examined epilepsy-related knowledge amongst YPWE (aged 6-19) and qualified nurses. Studies were found by searching two databases. The reference lists of these studies, as well as studies that had referenced these studies, were examined to make sure no relevant research was missed. Eighteen studies met the inclusion criteria and were included in the review.

Results

It was difficult to answer the research aims because the way that knowledge was measured and interpreted varied between studies.

Young People.

Gaps in knowledge were found in all studies. These studies were conducted in the USA, UK, Germany and Korea. Some YPWE held inaccurate beliefs about the causes of epilepsy, safety practices, contraception, and medication.

In a study from the USA, factors linked to increased knowledge included older age, Caucasian race compared to African American race, and employment of a parent in a professional occupation. Having parents present at appointments helped with knowledge attainment. However, not all young people wanted their parents at appointments. Information in simple language was helpful. Written and repeated information were useful. Additionally, the more prepared a child was to transition to adult services, the more epilepsy-knowledge they had. Level of stigma was also linked with knowledge. Interestingly, people with 'very low' levels of knowledge had

lower stigma scores than people with 'low' levels of knowledge. Some YPWE were reluctant to talk about seizures, this may have negatively impacted knowledge. In two studies, between 52-56.4% of YPWE said they wanted to be told more about epilepsy. However, in one study most YPWE were happy with their knowledge levels.

Nurses.

Gaps in knowledge were found in all studies. These studies were conducted in Greece, Japan, Turkey, Laos, India, Iran, Egypt, and Niger. There were specific knowledge-gaps related to the cause of epilepsy, the signs and symptoms of epilepsy, seizure management and safety practices.

Factors linked to nurses' knowledge varied across studies from different countries. Higher levels of education and income were linked to increased knowledge in a study from Turkey but not Iran. Having a relative with epilepsy was linked to better knowledge in a study in Iran but not Turkey. Older age was linked with increased knowledge in Niger, whereas younger age was linked with higher knowledge in a study from Iran. Age was not linked with knowledge in a study from Turkey. In one study of clinical nurses in Turkey, there was a relationship between knowledge and attitude (as knowledge increased, so did attitudes). Most nurses wanted additional information or training about epilepsy.

Discussion

Areas of knowledge were lacking amongst qualified nurses and YPWE in studies across the globe. Knowledge about mental health was not comprehensively investigated. Several factors impacted knowledge-levels. However, the quality of the studies was generally poor. Additionally, the measurement of knowledge varied across studies which made it difficult to make comparisons and conclusions. The surveys that were used were not always tested for reliability (consistency of a survey) or validity (the accuracy of the survey). Therefore, caution should be taken when interpreting the results of the systematic review. The development of a single, validated survey to assess knowledge across different countries would be useful. This would allow for more meaningful answers to the research questions.

Empirical Project

Introduction

YPWE have an increased risk of developing mental health difficulties compared to the general population and those with other physical-health conditions. There are effective psychological interventions for this population. However, they are not always used. Sharing information with YPWE and their parents helps them to make informed decisions about care and supports them to advocate for their mental health treatment. Sharing information is also important for patient empowerment. Despite these benefits, evidence suggests that YPWE have unmet information needs. There is a lack of research that looked at the information needs about mental health. Current guidelines suggest that information about emotional wellbeing should be shared with YPWE and their families. However, they do not say how or what should

be shared. This study aimed to identify the information needs and preferences regarding mental health and epilepsy for YPWE and their families. It also aimed to look at the differences between what YPWE and their parents were currently receiving and what they wanted to receive.

Methods

Eight parents of children with epilepsy and three YPWE were interviewed about their experiences of receiving mental health information, as well as their information needs and preferences. This is known as ‘qualitative’ research. Important ideas from the interview were identified and organised into themes. These themes described information needs and preferences regarding mental health, as well as the differences between the current provision of information and the desired provision of information.

Results

Five themes were developed:

1. ‘Responsibility placed on parents and young people’. This theme described how parents felt responsible for getting information and wanted more support with this process.
2. ‘Information provision is inadequate’. Many parents and YPWE believed that they had a lack of knowledge about mental health in epilepsy and had received poor mental health support. Some said this was because mental health

services and epilepsy services were separate. People wanted more integrated support.

3. 'The Role of Care Providers' described how people had received information. The importance of good relationships and equal power-dynamics with professionals was discussed. Many parents highlighted the importance of professionals listening and being respectful. Parents wanted professionals to provide more information about mental health.
4. 'What Is the Right Amount of Information?'
 - Some participants believed that not all information is good to know. Too much negative information could be overwhelming. Some thought that parents should be asked about what information should be shared with their child. The usefulness of information also impacted what people wanted to know.
 - There was uncertainty about when and how information should be shared amongst some parents.
 - Some participants said that they wanted to know all information about mental health as this could help them to prepare and plan.
5. 'Information Should Be Tailored to Individual Needs' was expressed by many. Preferences in the content, delivery and timing of information varied across participants. People wanted information that was clear to understand and from reliable sources. People said that the timing of information was important and this was likely to vary across individuals.

Impact, Integration and Dissemination

Both the systematic review and the empirical project provided information on topics that were relatively unknown. A common finding was that there were gaps in knowledge about epilepsy. The systematic review showed that there were knowledge gaps in YPWE and nurses around the world. The empirical paper showed gaps in knowledge regarding mental health in YPWE and parents. The empirical project also provided important information about YPWE's and parents' information needs and preferences. Both studies highlighted that factors that are unique to an individual can impact their need for information and knowledge-levels. Findings of both studies are important to YPWE, their families, clinicians, researchers, and people involved in creating policies and services for YPWE. Findings from both papers will be submitted to academic journals to reach as many people as possible. Findings will be shared with participants and with people that work with YPWE and their families.

Paper 1.

**Epilepsy-Related Knowledge Amongst Young People With Epilepsy and
Qualified Nurses: A Mixed Methods Systematic Review**

Systematic Review

Abstract

The purpose of this mixed methods review was to systematically review the research, published since 2010, that has examined the level of knowledge about epilepsy in qualified nurses and Young People with Epilepsy (YPWE). The review aimed to examine epilepsy-related knowledge levels and factors associated with knowledge. PsycINFO and Web of Science were searched using forward and backward citation searching, which yielded 970 studies after deduplication. Ten studies met eligibility criteria for nurses, and eight for YPWE (total N=18 studies). These were assessed for quality using the MMAT and CASP. Systematically addressing the research aims was challenging due to the heterogenous measures used to assess knowledge and variation in the reporting of knowledge across studies. Limited studies used reliable and valid instruments. Narrative synthesis of the data produced three themes: 'Knowledge of Epilepsy'; 'Desire for Further Information'; and 'Factors That Are Linked to Current Knowledge'. There were areas of epilepsy-related knowledge that were inadequate amongst qualified nurses across the globe. Such areas included general knowledge about epilepsy and the management and safety practices of nurses. Regarding YPWE, there were inadequacies in knowledge about epilepsy. Specifically, some YPWE held inaccurate beliefs regarding general knowledge about epilepsy, epilepsy management and safety practices, and contraception and childbearing in epilepsy. Knowledge about mental health in people with epilepsy was not comprehensively investigated. When asked, most nurses wanted more information/training on epilepsy. Most YPWE wanted additional information; however, one study reported mixed findings. Several factors impacted

knowledge-levels, although these varied across the globe. Further global research into epilepsy-related knowledge amongst YPWE and nurses, that utilises a homogenous, psychometrically sound instrument, is warranted. This would allow for more meaningful conclusions to be drawn across studies.

Introduction

Epilepsy impacts approximately 50 million people worldwide and has been defined as a noncommunicable, heterogenous condition, characterised by two or more unprovoked seizures (World Health Organisation [WHO], 2022). Approximately 40% of people who develop epilepsy annually are young people under the age of 15 (Guerrini, 2006). There are various classifications for seizure and epilepsy diagnoses and these are pivotal for improving understanding, communication, and discussion in people with epilepsy and clinicians (Falco-Walter et al., 2018). Despite being one of the most common chronic neurological conditions with clear classification systems, epilepsy carries misunderstanding and stigmatisation (Aaberg et al., 2017; Boer et al., 2008). The impact of epilepsy extends beyond seizures, with health-related quality of life including educational, social, physical and emotional aspects all being impacted (Beghi, 2016).

Within paediatric epilepsy literature, information exchange has been defined as the “active or passive process of exchanging or imparting information, knowledge and skills between healthcare professional and young people in routine clinic or healthcare encounters” (Lewis et al., 2010, p.2). The National Institute of Clinical Excellence (NICE) have highlighted the importance of timely information exchange for people with epilepsy and their families (NICE, 2022). Additionally, it has been advocated that every person with epilepsy should be educated about all aspects of their condition and accurate information is an essential part of person-centred care (Bell & Liu, 2001; England et al., 2012). Current frameworks of self-care have emphasised the

importance of educating young people to become experts in their own care by the time they transition into adult services (Lewis et al., 2010). The benefits of educating people with epilepsy and Young People with Epilepsy (YPWE) about their condition are well documented. For example, accurate knowledge aids psycho-social adjustment and can lead to an improved quality of life (QoL) (Lewis et al., 2010). Additionally, a group self-management, psychoeducation intervention could improve self-management of seizures, QoL and improve seizure control in adults with epilepsy (Smith et al., 2017).

Despite the clear recommendations and effective psychoeducation interventions, there is a considerable amount of evidence that suggests there are significant gaps in people's knowledge about epilepsy. Couldridge et al. (2001) conducted a systematic review with adults and YPWE and found that there were gaps in knowledge regarding personal and general aspects of epilepsy. Within their review, some papers assessed existing levels of knowledge and found that specific areas of poor knowledge included epilepsy specific safety regulations, types of epilepsy, photosensitivity, treatments, and medication. Two studies within their review showed that less than 50% of the subjects were content with their level of knowledge. This review was conducted over two decades ago and studies have since been published that highlight the lack of knowledge in adults with epilepsy. For example, in a multicentre cohort study of adults with epilepsy, it was concluded that patient's lacked information concerning premature mortality and status epilepticus and that these topics were not discussed by healthcare professionals (Schwab et al., 2021). A recent systematic review by Mahendran et al. (2017) explored the reasons for unmet needs (e.g., unmet physical health needs) in adults and YPWE. One reason for unmet

needs was difficulty accessing information, including information on women's health, medication, and alternative treatments. However, the studies pertaining to knowledge-level were published prior to 2010 or only investigated adults' information needs. Therefore, examining literature published since 2010 and with YPWE is warranted. Additionally, although Mahendran et al. (2017) alluded to deficits in knowledge, the included studies did not directly examine existing knowledge levels.

The epilepsy-related knowledge amongst systems around the YPWE have been more recently reviewed. For example, Nevin et al. (2020) conducted a systematic review on the knowledge of parents of children with early-onset epilepsy. It was concluded that parents had many unmet information needs. Additionally, a systematic review of teachers found that there were significant gaps in epilepsy-related knowledge (Jones et al., 2018). Given the lack of epilepsy-related knowledge amongst parents and teachers, it is possible that knowledge deficits also exist among children and YPWE, as parents are major sources of information and learning (Harden et al., 2021).

Regarding YPWE, Lewis et al. (2010) conducted a systematic review to investigate what was known to be effective in delivering information to YPWE and their parents, their experience of receiving information and the variables that impacted information exchange. They found that many children lacked knowledge about aspects of epilepsy, such as medication and contraception, and that the majority believed they received inadequate information from healthcare professionals. This review has not been updated since 2010. Resultantly, there is not a comprehensive

overview of the literature that investigates current knowledge levels of children and YPWE about their condition.

The Role of Clinicians in Delivering Information

Physician factors can also contribute to unmet information needs. In their review, Mahendran et al. (2018) reported eight papers that highlighted clinicians lacked knowledge about epilepsy-specific topics. However, this lack of knowledge was noted by patients, rather than clinicians themselves. Nevertheless, evidence has suggested a lack in epilepsy knowledge in physicians internationally and epilepsy-related knowledge gaps can lead to delays in timely support (England et al., 2012).

Healthcare professionals, including epilepsy specialists and non-specialist clinicians, are key providers of information. More specifically, nurses play an essential role in educating patients with epilepsy, caregivers, and families (Sample et al., 2006). Although their role varies, nurses around the world provide diverse care including education, access to advice and the promotion of independence in people with epilepsy (Prevos-Morgant et al., 2019). In the United Kingdom, Epilepsy Specialist Nurses (ESN) are employed in secondary and tertiary-care centres and are expected to have post-registration relevant experience; additionally, they are expected to comply with competency frameworks (Prevos-Morgant et al., 2019). However, the ESN is not a role that exists across all countries. In settings with sparse resources, nurses may be the only clinician to provide comprehensive support to people with epilepsy (Prevos-Morgant et al., 2019). Given the crucial role that nurses play in educating patients with epilepsy, and the negative impacts that lack of knowledge can

have on patients, it is important to better understand nurses' knowledge levels around the globe.

Summary and Rationale for the Current Review

A systematic review highlighted that YPWE received inadequate information about epilepsy from healthcare professionals (Lewis et al., 2010). However, this was conducted over a decade ago and it is likely that the literature has since been updated. Additionally, in their systematic review, Lewis et al. (2010) focused on *how* information can be optimally delivered to young people with epilepsy rather than current knowledge levels. More recently, literature has investigated the epilepsy-knowledge of parents, teachers and adults with epilepsy (Jones et al., 2018; Mahendran et al., 2017; Nevin et al., 2020). However, there has not been an updated review of the current knowledge levels of young people. Given the negative implications that lack of knowledge about epilepsy has on various domains, it is important to understand the current levels of knowledge amongst young people as well as the variables associated with their knowledge levels. In the UK, guidance on what information should be communicated to YPWE has been updated since 2010, with an increased focus on mental health (NICE, 2022). Internationally, the WHO have developed a programme, the mental health Gap Action Programme (mhGAP), that plans to scale up services for mental, neurological, and substance use disorders among low-and middle-income countries (WHO, 2016). For epilepsy, it aims to reduce the treatment gap through educating and training professionals. Therefore, there is a need for an updated review to understand existing knowledge levels in YPWE and professionals.

Additionally, evidence has suggested that physicians lack epilepsy-specific knowledge and this had negative implications on patients (England et al., 2012). Nurses play a key role in educating patients about epilepsy. In poorer-resourced services, nurses may have to educate and care for people with epilepsy without having had to meet a standardised competency frameworks or having had relevant experience. It would be beneficial to investigate the current knowledge levels of nurses regarding epilepsy worldwide, as this is relatively unknown.

Review Aims

The current systematic review aimed to investigate the knowledge levels of YPWE and qualified nurses in relation to epilepsy, as well as the variables that were associated with their knowledge.

Research questions:

1. What do qualified nurses know about epilepsy?
2. What are the variables associated with knowledge levels in qualified nurses?
3. What do young people with epilepsy, aged 6-19 years of age, know about epilepsy?
4. What are the variables associated with knowledge levels in young people with epilepsy?

Method

Systematic Literature Search Strategy

The databases PsycINFO and Web of Science were systematically searched in March 2022. Three categories of search terms were combined using Boolean operators, with ‘OR’ being used within concepts and ‘AND’ between concepts (Table 1). The search terms were reviewed by a librarian. For both databases the ‘English papers only’ limiter was applied. Within PsycINFO, the ‘exclude dissertations’ limiter was applied. As similar systematic review that investigated the information preferences in young people was published in 2010, only papers published since 01.01.2010 were considered. Forward and backward citation searching was conducted; reference lists of included studies and papers that had cited the included studies were searched manually.

Table 1

Search Terms

Concept	Search Terms	Searched in
Information needs and knowledge	"health information needs" OR "information needs" OR "information preferences" OR "health service needs" OR "health information" OR "health knowledge" OR "health information demands" OR "health patient education" OR "information	All fields

	preferences" OR "psychoeducation" OR "patient knowledge" OR "epilepsy knowledge" OR "knowledge about epilepsy" OR "knowledge of epilepsy" OR "education needs" OR "transition" OR "Understanding of epilepsy" OR "epilepsy understanding"	
(AND) Young people / Nurses	"Young people" OR child* OR minor* OR adolescen* OR teen* OR paediatric* OR clinician* OR nurse*	All fields
(AND) With Epilepsy	"epilepsy" or seizur* or "epileptic" or convulsions or "pwe" or epilep*	All fields

Study Eligibility

Table 2 outlines the inclusion and exclusion criteria applied. Regarding age, 19-years-old was selected a 'cut-off' age, as many young people transition to adult services after this time point. Additionally, similar age categories had been used in previous literature investigating the information needs of young people (Lewis et al., 2010). Intervention studies were excluded. Studies that *only* reported a single score, such as the average, to indicate knowledge were excluded as they would not have sufficiently allowed for the identification and evaluation of specific areas of knowledge amongst nurses and YPWE. Studies that reported a single, mean score were emailed to request participant responses on individual items. One study responded to the request (Smith et al., 2021).

Table 2.***Inclusion and Exclusion Criteria***

	Inclusion criteria	Exclusion criteria
Date	Published after 01.01.2010	Published before 01.01.2010
Language	Published in English	Non-English
Study Design	Quantitative studies that utilised any quantitative data collection and analysis method. Qualitative studies that utilised any method of data collection and method of qualitative analysis. Mixed methods studies.	Intervention studies that aimed to assess the efficacy of an intervention. Studies that asked participants to evaluate an intervention, such as a psychoeducation protocol or Application. Editorials, news/opinion pieces, conference proceedings, review papers, dissertations/theses, and letters.
Participants	Young people up to, and including, age 19 with a diagnosis of epilepsy. If a study included participants that were aged over 19, they were included if the mean age of participants was 19 or below. If a study included participants that were over 19 years of age, they were included if the data of young people aged 19 years or below could be extracted separately. If a study included other participants that were not a young person with epilepsy (e.g.,	Studies that included only people with epilepsy over the age of 19. Studies that included varying ages (including people over the age of 19) that did not specify the age of the participant that was linked to the data. Studies that examined the views of parents/caregivers only . Studies that examined the knowledge/information needs of

	<p>parents, siblings, clinicians) as well as a young person with epilepsy, they were considered if the information needs/knowledge of young people could be extracted separately.</p> <p>Qualified nurses. If a study included other healthcare professionals, they were considered if the information needs/knowledge of qualified nurses could be extracted separately.</p>	<p>unqualified nurses, nurses in training or nursing students.</p>
Outcomes	<p>The reported information needs by the young people/nurses and/or current knowledge level about epilepsy. As well as the facilitators/barriers to this information exchange.</p>	<p>Studies that did not report the information needs and/or current knowledge level of young people with epilepsy/nurses about epilepsy.</p> <p>Studies that only reported one overall score (e.g., mean score) to indicate knowledge.</p>

Study Selection Process

References were exported to the referencing software manager ‘EndNote Online’. Duplicate studies were removed through EndNote and by hand. The primary researcher screened the titles and abstracts of all potentially eligible studies against the inclusion and exclusion criteria. A second reviewer then independently checked 10% of all potentially eligible studies against the inclusion and exclusion criteria, to assess for inter-rater reliability. There was a lack of consensus on two

articles; disagreement was discussed until a consensus was reached. A third reviewer (the primary researcher's academic supervisor) also reviewed any disagreements. The primary researcher continued eligibility checks by reading the full text of the potentially relevant studies (N = 56). At this stage, any uncertainty about the eligibility of the studies was consulted with the third reviewer. The second reviewer checked 10% of the full-text articles, which were selected at random. There was complete agreement between the two reviewers. See Figure 1 for the study selection process.

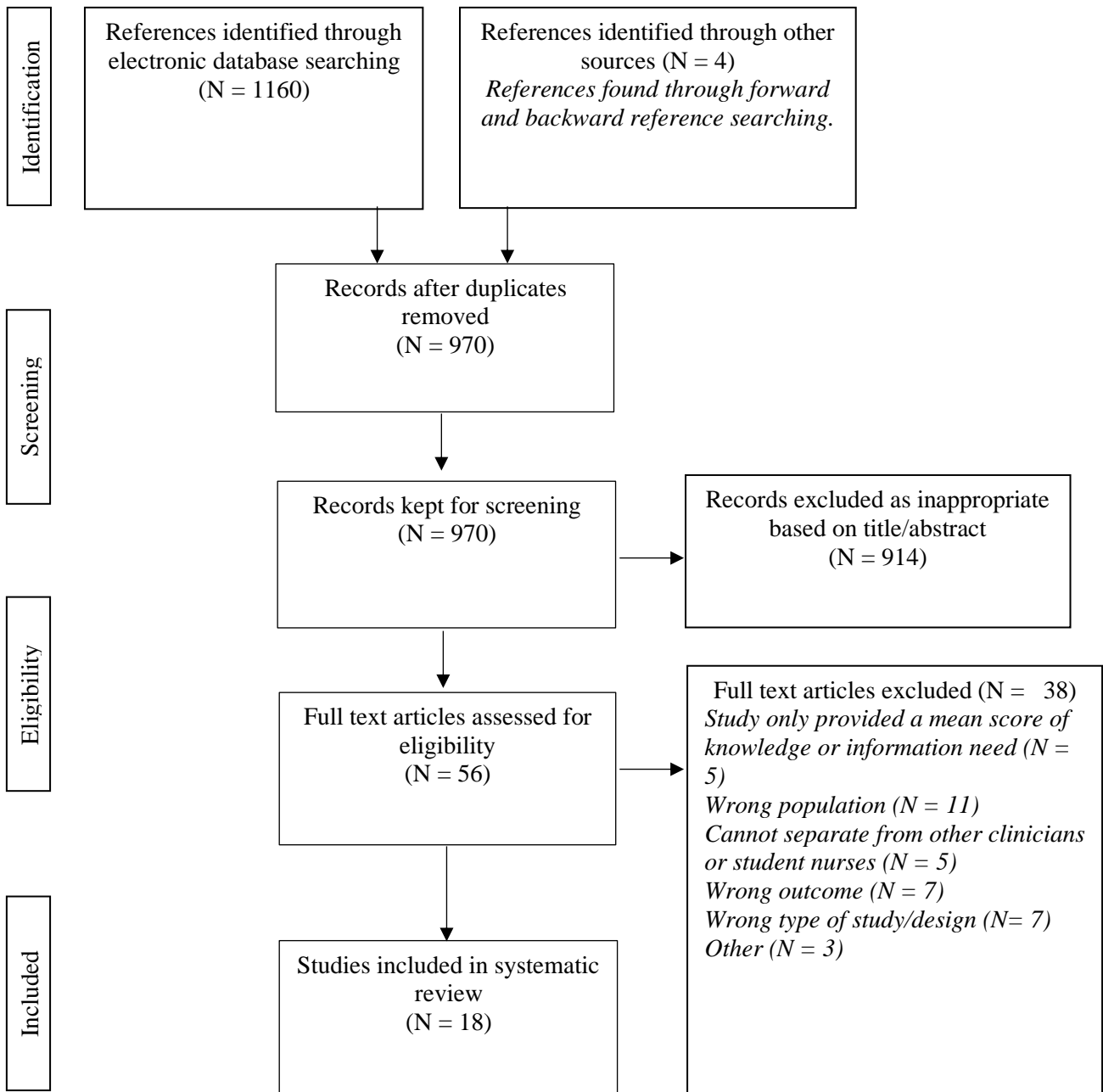
Data Extraction

Data extraction was piloted prior to data collection to ensure no relevant data was omitted. Data extracted from the 18 included studies was as follows: Author, Date, Country of Origin; Sample Characteristics/Sample Representativeness; Aim/Objective; Study Design; Data Collection Method; Measure of Knowledge/Psychometric Properties of the Measure; Response Rate, and results that were relevant to the research questions. Due to the potential ambiguity with obtaining results from qualitative research, the relevant themes, concepts, and quotes identified by authors within the 'findings', 'results', or 'discussion' sections were extracted.

For all the included studies, only data relevant to the systematic review's research questions was extracted. Any data related to the current knowledge or information needs was extracted. The second reviewer independently extracted data from two studies, any inconsistencies were resolved without the need for consultation from a third reviewer.

Figure 1.

Flow Diagram of the Systematic Search Process.



Quality Appraisal

A suitable quality appraisal tool was selected according to the type of study design. Cross-sectional studies and mixed methods studies were assessed using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018b). The MMAT requires the reviewer to select the appropriate criteria for the study design. Different aspects of qualitative, quantitative and mixed methods studies were examined, and a rating of ‘yes’, ‘no’ or ‘unsure’ was applied to five different criterion. These ratings were scored 1, 0 or 0, respectively. The scores for each study design were added together to provide a percentage score out of 100 for each type of design. Each score of ‘1’ equated to 20% of criteria met. For example, 3 scores of ‘1’ would equate to 60% of criteria met (Hong et al., 2018b).

For mixed methods studies, the qualitative and quantitative elements of the studies were assessed independently and then the key elements of the mixed methods study were assessed (see Table A2 for the specific MMAT criteria). This resulted in 15 criteria to rate. When considering the overall quality rating score of mixed-method studies, the overall quality of a combination could not exceed the quality of its weakest component (Hong et al., 2018b).

Item 4.4 required the rater to comment on the risk of nonresponse bias. Due to the ambiguity with operationalising what constitutes as ‘low’ response rates, the author used Prince's (2012) categorisation which defines a response rate that falls below 70% as a ‘critical issue’. As the response rate was not reported in most studies, the researcher calculated this manually where possible. Response rates of less than

70% were rated as '0', above 70% as '1' and '0' if no data was provided to calculate this score.

Studies deemed to be of low methodological quality were not excluded as the purpose of the quality assessment was to support the interpretation of the evidence (Mooney et al., 2021). However, the level of bias was considered at the synthesis stage to consider how this may affect the overall interpretation of the extracted data, as recommended by Hong et al., (2018b).

Qualitative studies were appraised using the qualitative checklist of the Critical Appraisal Skills Programme (CASP) tool (CASP, 2018). The CASP checklist has been recommended for novice researchers (Bennett et al., 2017) and allows for a structured approach to identify the strengths and weaknesses to assess the usefulness of a study's findings (Singh, 2013).

Data Synthesis

Due to the heterogenous nature of the included studies, it was not appropriate to conduct a meta-analysis or use statistical methods to synthesise it. A narrative synthesis of the included studies was conducted using Popay et al.'s (2006) guidance. This has been defined as:

“an approach to the systematic review and synthesis of findings from multiple studies that relies primarily on the use of words and text to summarise and explain the findings of the synthesis. Whilst narrative synthesis can involve

the manipulation of statistical data, the defining characteristic is that it adopts a textual approach to the process of synthesis to ‘tell a story’ of the findings from included studies” (Popay et al., 2006, p.5).

Within the guidance, the authors highlighted a general, iterative framework.

Within each element, Popay et al. (2013) suggested various approaches can be taken (Higginbottom et al., 2013). Four elements were considered:

1. *Development of a theory of how the intervention works, why it works and for whom.* This was not relevant for the current review as the researchers sought to understand people’s current knowledge, information needs and barriers/facilitators rather than assessing an intervention.
2. *Development of a preliminary synthesis of the findings of included studies.* This was achieved through tabulating the extracted data. This allowed the researcher to visualise textual summaries of the studies and their results.
3. *Exploration of the relationships in the data.* The homogeneity and heterogeneity across the studies were investigated to identify patterns across the results. The data was then grouped into themes in consideration of the research questions. More specifically, line-by-line coding of data was conducted and coded data was organised into descriptive themes.
4. *Assessment of the robustness of the synthesis.* When drawing overall conclusions, the methodological quality of the included studies was considered.

Results and discussion sections were structured in line with Cochrane guidance (Ryan, 2013).

Results

Characteristics of Included Studies

Ten studies investigated the knowledge and information needs of nurses. Of these, nine were cross-sectional, and were conducted in Greece, Japan, Turkey, Laos PDR, India (2), Iran, Egypt and Niger and one was mixed methods which was conducted in Japan. Sample sizes ranged from 41-640, and they were recruited from hospitals, schools, internal medicine clinics, prefectures, health facilities and contacted through a Chief Medical Officer.

Eight studies investigated YPWE. Of these, five were cross-sectional, one mixed method, and two qualitative. There were conducted in the USA (3), UK (2), Germany (2), and Korea. Sample sizes ranged from 23- 243, and they were recruited through hospitals, an outpatient neurology clinic, social media platforms, and neuropaediatric departments. Study characteristics are included in Table 3.

Measurement of Knowledge

There was considerable heterogeneity in the ways in which knowledge was measured.

Cross Sectional Studies

Most of the quantitative, cross-sectional studies used a bespoke measure that was developed by the research team which was informed by previous literature, pre-existing questionnaires or developed independently by the researchers (Abbas et al., 2019; Agarwal et al., 2014; Assadeck et al., 2020; Buddhiraja et al., 2020; Harimanana et al., 2013; Hegazy et al., 2019; Nishina & Yoshioka, 2018; Pausheck et al., 2016; Prabhu et al., 2021; Toli et al., 2013; Woltermann et al., 2020). Three studies utilised pre-existing questionnaires (Dayapoglu & Tan, 2016; Ryu et al., 2015; Smith et al., 2021), two of which were translated from their original language or modified to better reflect language (Ryu et al., 2015; Smith et al., 2021). Ryu et al., (2015) and Smith et al., (2021) used adapted versions the Epilepsy Knowledge Profile (EKP) (Jarvie et al., 1993). Agarwal et al., (2014) developed their own survey which was informed by the EKP.

Regarding the psychometric properties of the measures, four studies utilised measures that were both reliable and valid (Abbas et al. 2019; Buddhiraja et al.,2020; Dayapogly & Tan, 2016; Toli et al., 2013). Four studies utilised a measure that was only tested for validity (Agarwal et al., 2014; Harimanana et al., 2013; Prabhu et al., 2021; Woltermann et al., 2020) and two used a measure that had only been tested for reliability (Hegazy et al., 2019; Smith et al., 2021). Four studies utilised measures that had not been assessed for reliability or validity (Assadeck et al., 2020; Nishina & Yoshioka, 2018; Pauschek et al., 2016; Ryu et al., 2015). Two studies utilised pre-existing measures which were deemed to be psychometrically sound; however, these were translated from their original language. Ryu et al. (2015) had not examined the

validity or reliability of the measure in Korean populations and Smith et al.'s (2021) modified version was deemed to be reliable but validity was not examined.

See Table 3 for the psychometric properties of the measures utilised by studies.

Mixed Methods Studies

Both mixed methods studies developed their bespoke own surveys. Terada et al.'s (2020) survey was informed by an expert panel. However, the psychometric properties of the survey were not discussed and thus assumed to not have been examined. Manski and Dennis (2014) did not report how their survey was developed nor did they report the psychometric properties of the questionnaires.

Qualitative Studies

Regarding the two qualitative studies, Harden et al. (2021) developed their interview schedule after informal discussions with service-users and professionals. The interviews examined their experience of epilepsy and their perceptions of their clinic appointments. Lewis and Noyes (2013) did not comment on how the interview schedule was developed. Their interview schedule broadly examined the young person's experience of transition services, including their knowledge and information exchange.

Reporting of Knowledge Across Studies

There was variation in the ways in which knowledge was quantified across studies, likely due to the varied instruments used. Results were frequently based on the reporting of single items (for example, percentages of correct scores on a question) or arbitrary, non-standardised categorisations of data. For example, Terada et al. (2020) concluded that participants “understand epilepsy relatively well”; however, they did not use ‘cut-off’ points based on standardised measurements such as quartiles to operationalise their categorise. Five studies reported the classification system they used to categorise data (for example, percentiles, quartiles, tertiles or cut-off ranges).

Quality Assessment

Quantitative and Mixed Methods Designs

Overall quality scores are shown in Table 3. Three studies scored 20%, eight studies scores 40%, two studies scored 60% and three studies scored 80%. The mean quality score was 46.3%.

One of the sixteen studies (Harimanana et al., 2013) utilised probability sampling, with the remainder using non-probability sampling which limited external validity (Forster, 2001). Eight of the sixteen studies did not include a sample that was representative of the target population, as shown in Table 3. As discussed previously, twelve studies did not utilise measures that were both reliable and valid. Response rates ranged from 52.2%-100%. Of the studies in which a response rate could be

calculated, only four gave reasons for non-responses such as participants not understanding the research questions (Pauschek et al., 2016; Dayapoğlu & Tan, 2016; Nishina & Yoshioka, 2018 ; Smith et al., 2021). No studies commented on the potential implications of non-response bias and missing data on their conclusions. The statistical analysis of the studies was justified.

Within both mixed methods studies, the qualitative criteria were rated higher for quality than the quantitative elements. Terada et al.'s (2020) output data from the two designs was poorly integrated. Despite the authors reporting that the qualitative analysis would clarify participant's quantitative answers, this was not clearly demonstrated.

Qualitative Designs

Both studies appropriately chose qualitative methodology and clearly stated their research aims. Their research design, recruitment strategy and data collection were appropriate. The relationship between researcher and participant was clearly discussed, and ethical issues considered. Data was rigorously analysed by Lewis and Noyes, (2013). However, Harden et al., (2021) achieved an 'unclear' rating due to a lack of critical examination of their own bias in the analysis and presentation of data. Both studies clearly stated their findings and provided valuable research.

Appendix A shows the criteria for the MMAT (Table A2), individual quality ratings for the MMAT (Table A1), and CASP scores (Table A3).

Table 3.

Study Characteristics

Author, Date, Country of Origin	Sample Characteristics	Aim/Objective	Study Design, Data Collection Method	Measure of Knowledge, How Instrument Was Created	Credibility of Instrument	Response Rate	Representativeness of Sample	Quality Rating
Agarwal et al. (2014) USA	YPWE Mean age (range) = 15.2 (13-18) N = 165 51.5% Female	To evaluate the understanding of adolescents about epilepsy.	Cross-sectional (Survey)	Knowledge assessed via the SAFETY questionnaire. Female participants answered questions on Reproductive Health. Bespoke survey developed.	Valid.	94.3%	Not representative. <i>Target population:</i> adolescents with epilepsy. <i>Sample:</i> adolescents with epilepsy from one institution (self-selecting).	40%
Manski & Dennis (2014) USA	<u>Survey Sample</u> Female teenagers with epilepsy. Mean age (range) = 18 (13-19) N = 114 100% Female <u>Focus Group Sample</u> Female teenagers with epilepsy Mean age (range) = 19 (15-20) N = 26 100% Female	To examine the knowledge and perceptions of interactions between AEDs and contraception. To examine contraceptive decision-making and experiences. To examine contraceptive support. To identify recommendations for improving contraceptive service-delivery.	Mixed methods (Survey, quantitative) (focus group, qualitative)	The first phase of the study was an online survey, the second phase of the study was an online focus group. Bespoke survey developed.	No information.	Cannot calculate	Representative. <i>Target population:</i> female teenagers with epilepsy. <i>Sample:</i> female adolescence that were recruited online (self-selecting).	40%

Pauschek et al. (2016)	YPWE Mean age (range) = 11.9 (7-18) N = 84 Germany 56% Female	To identify children's knowledge about epilepsy, practical knowledge about treatment and safety precautions, and how they cope with their disease.	Quantitative Cross-sectional (Structured interview and drawing analysis)	Knowledge was assessed via structured interview. Participants were then asked to draw a picture about their self-assessment of epilepsy. Bespoke interview schedule developed. Informed by existing questionnaire (not specified).	No information.	89%	Not representative. <i>Target population:</i> Children with epilepsy <i>Sample:</i> young people from <u>one</u> neuropsychiatric department (self-selecting).	40%
Ryu et al. (2015)	YPWE and their mothers. Korea <u>Sample of YPWE</u> Mean age (range) = 15.1 (13-18) N = 243 48% Female	To identify the level of knowledge about epilepsy and the perception of stigma in adolescents and their mothers. To examine if poor epilepsy knowledge and maternal stigma influence the presence of stigma among adolescents.	Cross-sectional (Survey)	Knowledge about epilepsy was assessed via the medical questions of the EKP. Adapted EKP questionnaire used.	Although EKP is psychometrically sound, the authors used a translated version which was not validated.	Cannot calculate	Representative <i>Target population:</i> Korean AWE and their mothers <i>Sample:</i> multicentre study involving 25 secondary or tertiary hospitals in Korea (self-selecting).	40%
Harden et al. (2021)	Children with epilepsy Mean age (range) = 10.1 (8-14) N = 23 57% Female UK	To gain insight into children's understanding of epilepsy, seizures, medication, and their role in clinical appointments. To investigate the implications of the results on clinical practice.	Qualitative (Semi-structured interview, observation of clinical appointment)	Knowledge of epilepsy was collected at three points with children – a semi-structured interview, an observation of a clinic appointment and through a second semi-structured interview. Qualitative interview schedule developed	N/A	N/A	N/A <i>Sample:</i> YPWE at two hospital sites	90%

Lewis & Noyes (2013)	YPWE and their parents. <u>Sample of YPWE</u>	To explore communication, information needs, and experiences of knowledge exchange during transition from child to adult services.	Qualitative comparative embedded case study, (Interviews and focus group)	Knowledge and experience were assessed through a mode of interview that was selected by participants (e.g., group interview, focus group or individual interview). Qualitative interview schedule developed	N/A.	N/A	N/A <i>Sample:</i> YPWE at two hospitals	100%
UK	Mean age (range) = N/A (13-19) <i>N</i> = 30 N/A% Female							
Wolterman et al. (2020)	Children with epilepsy. Mean age (range) = N/A (6-17) <i>N</i> = 100 46% Female	To investigate perspectives and attitudes towards rescue and long-term epilepsy medication. To explore how/what information children would include in their consultation.	Quantitative Cross-sectional (Structured interview and drawing analysis)	Knowledge was obtained through a structured interview with children regarding their anticonvulsant medication. They were also asked to draw a picture called “me and my medication”. Bespoke structured interview schedule developed.	Informed by expert panel. Valid.	Cannot calculate	Not representative. <i>Target population:</i> YPWE. <i>Sample:</i> young people from two university hospitals (self-selecting).	20%
Germany								
Smith et al. (2021)	YPWE. Mean age (range) = 17.3 (13-25) <i>N</i> = 82 53.7% Female	To compare transition readiness of youth with epilepsy by participant demographic variables To compare transition readiness by epilepsy characteristics To compare transition readiness by perception of need for transfer, and apply the SMART model	Cross-sectional (Survey)	Knowledge was assessed using a modified 47-item version of the EKP. Modified version of EKP to ‘better reflect language’.	Psychometric properties of EKP sound. However, utilise modified version that had only been assessed for reliability.	92.1%	Not representative. <i>Target population:</i> adolescents and young adults with epilepsy. <i>Sample:</i> young people from one paediatric hospital (self-selecting).	40%
USA								

Toli et al. (2013)	Registered school nurses	To examine the relationship between knowledge and attitudes of nurses and the frequency of accidents caused by epilepsy in school pupils.	Cross-sectional (Survey)	Knowledge was assessed using a questionnaire.	Piloted beforehand Reliable. Valid.	85% for special education school nurses and 77% for mainstream school nurses	Representative <i>Target population:</i> school nurses in Greek schools <i>Sample:</i> recruited from 226 primary and secondary special education schools and 94 secondary education vocational schools from all Greek prefectures (self-selecting).	80%
Greece	Mean age (range) = N/A (N/A) N = 306 83.4% Female			Bespoke survey developed. Based on previous literature.				
Terada et al. (2020)	Registered school nurses	To identify support system issues for students with epilepsy and improve communication between schools and medical services.	Mixed methods (Survey, closed and open ended).	A questionnaire was used to assess knowledge.	Informed by expert panel. Valid.	71.1%	Representative <i>Target population:</i> nurse teachers in Japan. <i>Sample:</i> recruited from 900 nurse teachers. 602 responded from mainstream schools, 34 from Special educational needs schools, and four from other schools (self-selecting).	60%
Japan.	Mean age (range) = N/A (N/A) N = 640 N/A% Female			Bespoke survey developed.				
Dayapoğlu & Tan, 2016	Clinical nurses	To assess epilepsy knowledge and attitudes of nurses working at a hospital in eastern Turkey.	Cross-sectional, (Survey)	Knowledge of epilepsy was assessed using the Epilepsy Knowledge Scale, a 16-item questionnaire.	Reliable Valid	88.5%	Representative <i>Target population:</i> nurses working at a university hospital located in eastern Turkey. <i>Sample:</i> nurses from internal medicine clinics at a university	80%
Turkey.	Mean age (range) = N/A (N/A) N = 85 87.1% Female			Pre-developed questionnaire – Epilepsy Knowledge Scale.				

							hospital. (self-selecting).	
Nishina & Yoshioka (2018)	Home healthcare nurses	To examine the knowledge, attitudes and practices of home healthcare nurses in the Sanin region of Japan in relation to epilepsy.	Cross-sectional (Survey)	Knowledge was assessed via a questionnaire that examined knowledge of epilepsy, as well as attitudes and practices	No information.	52.2%	Representative	40%
Japan.	Mean age (range) = 48.9 (N/A) N = 285 N/A% Female			Bespoke survey developed. Based on previous literature (not specified).			<i>Target population:</i> nurses in the Sanin region of Japan. <i>Sample:</i> distributed to nurses across the Sanin region of Japan (self-selecting).	
Harimana na et al., (2013)	Healthcare workers, including nurses and physicians	To assess the practices and knowledge of health workers in the Lao PDR towards epilepsy	Cross-sectional (Survey)	Knowledge was assessed using a 55-item survey.	Piloted for Validity	100%	Representative	80%
Laos.	<u>Sample of nurses</u> Mean age (range) = N/A (N/A) N = 140 87.1% Female	To assess patient attendance at health facilities.		Bespoke survey developed. Based on existing surveys (not specified).			<i>Target population:</i> health workers in the Lao PDR <i>Sample:</i> recruited from 11 province hospitals; 9 district hospitals; and 30 health facilities. All enrolled staff participated (self-selecting)	
Buddhiraj a et al. (2020)	Auxiliary nurse midwives, medical officers, and accredited social health activists.	To identify levels of knowledge, attitudes, and practices regarding epilepsy among healthcare providers in a North-Western Indian district.	Cross-sectional (Survey).	Knowledge assessed using a survey called the Knowledge, Attitude and Practice regarding epilepsy.	Scripted by experts. Reliable Valid	Cannot calculate	Not Representative	40%
India	<u>Sample of auxiliary nurse midwives</u> Mean age (range) = 41 (22-58) N = 120 100% Female			Bespoke survey developed.			<i>Target population:</i> primary healthcare providers in a North-Western Indian district. <i>Sample:</i> Respondents were contacted through the District Chief Medical Officer. People working outside of urban limits excluded.	

Abbas et al. (2019)	Clinical nurses	To identify the knowledge and attitude of nurses affiliated to Babol University hospitals regarding epilepsy and its related factors.	Cross-sectional (Survey).	Knowledge was assessed using a questionnaire. Bespoke survey developed. Based on existing surveys (not specified). Translated to Persian.	Valid. Reliable.	Cannot calculate	Representative	60%
Iran	Mean age (range) = N/A (<25->34) N = 500 79% Female						<i>Target population:</i> nurses of hospitals affiliated to Babol University of medical sciences. <i>Sample:</i> 500 nurses working at educational hospitals of Babol (self-selecting)	
Prabhu et al., (2021)	Clinical nurses	To assess the knowledge, attitude, and practices regarding epilepsy among nurses.	Cross-sectional (Survey)	Knowledge was assessed through interviewing nurses using a 50 item questionnaire. Bespoke survey developed.	Validity Piloted to test for accessibility.	Cannot calculate	Not Representative	20%
India	Mean age (range) = 30 (20-58) N = 213 96% Female						<i>Target population:</i> nursing staff in India. <i>Sample:</i> Participant's recruited from one institution- tertiary care teaching hospital in South India.	
Hegazy (2019)	Paediatric nurses	To assess the quality of knowledge and practice of Tanta University nurses regarding epilepsy.	Cross-sectional (Survey)	Knowledge was assessed via semi- structured questionnaire. Bespoke survey developed. Based on a version of Nishina & Yoshioka's questionnaire.	Reliability.	Cannot calculate	Representative	40%
Egypt	Mean age (range) = 25.78 (20-<30) N = 41 NA% Female						<i>Target population:</i> paediatric nurses at an in-patient paediatric department affiliated to Tanta university hospital (TUH), Egypt. <i>Sample:</i> 41 nurses from TUH inpatient department.	
Assadeck et al (2020)	Clinical nurses, including student nurses (only data from non-student nurses collected)	To assess knowledge, attitudes, and practices about epilepsy among nurses.	Cross-sectional (Survey)	Knowledge was assessed via a self-administered questionnaire. Bespoke survey developed.	None reported.	Cannot calculate	Not representative	20%
Niger							<i>Target population:</i> nurses in the city of Niamey, Niger. <i>Sample:</i> does not state where or how they	

Mean age (range)
= 32.88 (17<58)
N = 98
70.4% Female

To understand gaps
in their knowledge
To create
recommendations to
improve the quality
of care.

recruited (e.g., from
multiple hospitals or
one hospital?).
However,
generalisability listed
as limitation as they
only recruited public
sector nurses.

Note. SAFETY = Safety, Awareness, and Familiarity regarding Epilepsy in Teenage Years; EKP = Epilepsy Knowledge Profile; AED = Antiepileptic Drug.

Analysis Of the Findings

It was difficult to conduct a systematic analysis of the data or comment on overall levels of knowledge due to the differing measures of knowledge that were used. However, the relationships within and between studies were synthesised using narrative synthesis. Three themes were developed: ‘Knowledge of Epilepsy’; ‘Desire for Further Information’; and ‘Factors That Are Linked to Current Knowledge’.

Knowledge Of Epilepsy

Nurses.

Six of the ten studies investigating nurses’ knowledge broadly categorised knowledge levels, although these were based on arbitrary judgements. Significant knowledge gaps were identified in most of these studies. The remaining four studies that investigated nurses’ knowledge did not categorise overall knowledge levels.

Dayapoğlu and Tan (2016), Terada et al. (2020) and Toli et al. (2013) described nurses’ knowledge as satisfactory. However, amongst school nurses, there were specific gaps in knowledge regarding the presentation of epilepsy in students (Terada et al., 2020) and 79.3% believed they had knowledge gaps to practice school nursing with YPWE (Toli et al., 2013).

Conversely, Prabhu et al (2021) concluded that, overall, levels of knowledge were 'low' in their study of 213 clinical nurses. More specifically, 50.7% had 'poor knowledge', 13% 'fair' and 36.2% 'good knowledge' according to tertiles. Similarly, Hegazy's (2019) study of paediatric nurses revealed 'inadequate' levels of knowledge; overall, 95.1% of the sample showed a 'poor' score of knowledge about epilepsy. In their study of home-healthcare nurses, Nishina and Yoshioka (2018) concluded that nurses also had 'inadequate' knowledge of epilepsy regarding epilepsy in dementia and corresponding epileptic seizures.

Due to the disparate and subjective categorisations of knowledge across studies, specific areas of knowledge were broadly synthesised where possible.

Nurses' General Knowledge About Epilepsy.

All studies asked about the aetiology of epilepsy. In five studies, which included clinical and school nurses across Eastern countries and Niger, many correctly identified epilepsy as a neurological condition. Most nurses (84.8%) in Abbas et al.'s (2019) study knew that seizures were the result of abnormal electrical discharges in the brain. Conversely, most auxiliary midwife nurses provided incorrect responses to questions regarding the cause of epilepsy (Buddhiraja et al., 2020), and over 75% of the paediatric nurses showed 'poor' levels of knowledge related to epilepsy causes, definitions and triggers (Hegazy, 2019). Harimanana et al. (2013) investigated the epilepsy knowledge levels of healthcare staff, including nurses. Although they noted 52.4% of nurses knew 'any cause' of epilepsy, they did not

specify if these were correct which made it difficult to draw conclusions about the knowledge.

Regarding mental health in epilepsy, seven studies asked whether epilepsy was caused by mental illness. Within Toli et al.'s (2013) study, 76% of school nurses knew that epilepsy was not caused by "mental disorders and mental retardation" (Toli et al., 2013, p.334). Terada et al. (2020) also investigated school nurses' knowledge and found that 0.3% listed epilepsy as a psychiatric disorder. Bachelor graduate nurses (4%) and college patent nurses (14.3%) believed that epilepsy was caused by mental illness (Assadeck et al., 2020). Similarly, in studies from Japan and India, home healthcare nurses (24.6%), clinical nurses (29%) and auxillary midwife nurses (20%) incorrectly believed epilepsy was caused by mental illness (Nishina & Yoshioka, 2018; Prabhu et al., 2021; Buddhiraja et al., 2020, respectively). Amongst 41 paediatric nurses in Egypt, 9.8% believed that epilepsy was caused by mental illness (Hegazy et al., 2019). Furthermore, 67.5% of auxiliary midwife nurses believed that people with epilepsy should be screened for depression (Buddhiraja et al., 2020). Conversely, only 30.5% knew that people with epilepsy are at a higher risk of depression, whereas 87% opined that people may experience anxiety about having a seizure (Nishina & Yoshioka, 2018). Taken together, this indicates a gap in knowledge about mental health in epilepsy.

Within some studies, a small percentage of nurses held inaccurate, negative beliefs such as people with epilepsy are sinners, under the influence of supernatural factors or were 'contagious' (Abbas et al., 2019; Assadek et al., 2020; Harimanana et al.; 2013; Hegazy, 2019; Nishina & Yoshioka, 2018; Prabhu et al., 2021). Notably,

these studies were conducted in Iran, Niger, Laos, Egypt, Japan and India. With the exception of Japan, these are all considered developing or least developed countries (United Nations, 2014).

Regarding the signs and manifestations of epilepsy, very few (6.5%) clinical nurses and only a small number (15.5%) of school nurses knew all the clinical manifestations of epilepsy (Prabhu et al., 2021; Toli et al., 2013, respectively). Whilst 90.9% of Japanese home healthcare nurses correctly selected “convulsions and shaking” as sign of epilepsy, only 12.3% correctly selected “rising epigastric sensation”, indicating gaps in nurses’ knowledge about the less the common signs of seizure (Nishina & Yoshioka, 2018). Similarly, in a study of auxiliary nurse midwives, gaps in knowledge were identified (Buddhiraja et al., 2020). Over half (62.4%) of Turkish clinical nurses knew that it could be difficult to recognise certain types of seizure (Dayapoğlu & Tan, 2016).

Nurses’ Management of Epilepsy and Safety Practices.

The majority (84.7%, 89.8%, 95.1%, respectively) of clinical and paediatric nurses knew that seizures could be controlled by medication. However, a lower percentage (55.3%, 35.6%, 17.1%) knew brain surgery could stop seizures in some people (Dayapoğlu & Tan, 2016; Abbas et al., 2019; Hegazy 2019, respectively). Gaps in knowledge regarding medication were found. For example, in a survey of 120 auxiliary nurse midwives in India, 20% did not understand the implications of medication adherence (Buddhiraja et al., 2020). Out of 213 clinical nurses in India, 37% were unfamiliar with epileptic drugs and 42% did not know medication side

effects (Prabhu et al., 2021). In a survey of nurses in Laos PDR 28.6% of nurses knew of any antiepileptic drug (Harimanana et al., 2013).

Most of the nurses believed in modern medicine as a management option for epilepsy. However, a lesser number of clinical nurses residing in Iran, Niger, and Egypt also believed in ‘alternative’ modalities of treatment such as acupuncture and traditional medicines (Abbas et al., 2019; Assadeck et al., 2020; Hegazy, 2019). Only 42.1% of nurses from Laos PDR believed in modern medicine (Harimanana et al., 2013) and a small percentage of nurses in India also endorsed traditional/homeopathic treatment for epilepsy (Buddhiraja et al., 2020; Prabhu et al., 2021).

Regarding safety practices towards those with epilepsy, results were varied across studies. In a survey of school nurses in Greece, there were ‘concerns’ regarding their knowledge about the preparedness to respond to seizure-related emergencies and knowledge about specific intervention practices were low. However, 62.9% correctly identified the main safety-related goal when a child experiences a mild seizure (Toli et al., 2013). Similarly, most (92.7%) paediatric nurses in Egypt achieved an ‘unsatisfactory’ score in relation to their epilepsy management practice (for example, first aid management) before, during and after a seizure (Hegazy, 2019). In a study of clinical nurses, 35.7% reported not knowing what they would do if a person had a seizure (Assadek et al., 2020).

Overall, correct response rate to seizure response was high in home-healthcare nurses although specific gaps in knowledge existed (Nishina & Yoshioka., 2018). Terada et al. (2020) investigated school nurses’ knowledge regarding safety and first

aid with 85.9% reporting that they would calmly observe the seizure and 75.3% would secure the airway. Overall, 79% of nurses knew appropriate first aid for their students. Prabhu et al. (2021) concluded that more than half (53%) of the clinical nurses surveyed followed good practice during a seizure. Buddhiraja et al. (2020) asked various questions related to safety, with correct response rates varying between 65%- 92.5%. They did not give an overall interpretation of safety practice.

Inappropriate practice was highlighted. For example, 29.8% of home-healthcare nurses in Japan believed that something should be placed in person's mouth and 2.5% said the person should be shook when having a seizure (Nishina & Yoshioka, 2018). Similarly, 0.9% of school nurses in Japan also believed something should be placed in the mouth (Terada et al., 2020). Although these are relatively small percentages, they still highlight dangerous practice. Concerningly, a small percentage of nurses in India and Turkey endorsed the belief that making people smell shoes or onions, spilling water on people or making them drink water can stop seizures (Buddhiraja et al. 2020; Dayapoğlu & Tan, 2016). In a study of clinical nurses in India, faulty practices such as placing a metallic object in the patient's hand (44%) and administering oxygen (67%) were described (Prabhu et al., 2021).

Young People.

In a survey with 165 YPWE from one institution in the USA, overall 'poor' levels of knowledge were found (Agarwal et al., 2014). A survey with 243 Korean YPWE across 25 hospitals also yielded similar findings (Ryu et al., 2015). Although an overall knowledge score was not provided, 30 YPWE in the UK participating in an

interview/focus group had misinformation and most lacked important knowledge about epilepsy and lacked a clear understanding of epilepsy (Lewis & Noyes, 2013). Also in the UK, through interviews with 23 YPWE, it was concluded that children's level of knowledge was variable but adequate in the context of everyday life, despite gaps being evident (Harden et al., 2021).

Due to the disparate and subjective categorisations of knowledge across studies, specific areas of knowledge were broadly synthesised where possible.

Young People's General Knowledge About Epilepsy.

In a structured interview with young people (aged 7-18) in Germany, 75% were able to correctly name their disease. However, 42% did not know any cause of epilepsy and 10% believed epilepsy was contagious (Pauschek et al., 2016). Similarly, in a survey with 82 young people (mean age 17.3), the belief that epilepsy was infectious was endorsed by two young people (Smith et al., 2021).

In a series of focus groups with young people (aged 8-14) in the UK, some YPWE identified the involvement of the brain as a cause of epilepsy. However, physiological language was rarely used and knowledge of epilepsy was linked with treatment (for example, "It's me and there's a tablet... and there's my little tablets. That's what it is. Epilepsy", Harden et al. (2021), p.4). In a survey with young people (aged 13-18) in Korea, 60% believed that epilepsy was caused by mental illness (Ryu et al., 2015); similarly, 18% of young people in a study from the USA shared this belief (Smith et al., 2021).

Epilepsy Management and Safety Practices.

In a structured interview of 100 children in Germany (aged 6-17), it was found that most thought their medication was helpful (87%) and 66% were able to give an explanation as to why it was important. Of those prescribed rescue medication, 24% did not know about it. Overall, misconceptions in children's medication-knowledge existed (Woltermann et al., 2020). Also in Germany, through interviewing YPWE, it was found that most of the children knew whether they took long-term medication (96%), with 88% indicating when they take it and 52% knowing the name. Additionally, 64% knew that their medication aimed to prevent seizures, but 12% believed that it would cure epilepsy. Overall, the authors concluded that children showed 'rather good' knowledge about medication (Pauschek et al., 2016). Within Ryu et al.'s (2015) study, at least 80% of respondents answered items related to the importance of adherence to medication correctly. Harden et al., (2021) found that many children discussed medication in relation to its preparation and all gave some estimation of their dose. Most were able to describe why they took medication, the desired impacts, and the importance of medication adherence. Some disclosed the side effects from their medications. Smith et al. (2021) also asked a series of questions regarding medication. Of note, 90% of respondents did not know that it is acceptable to take two doses of medication if a day is missed.

Within Agarwal et al.'s (2014) questionnaire, questions related to 'Safety', such as 'it is ok to take a bath alone', were asked. The correct response rate for the 'Safety' items were 53.9% which was indicative of a poor score; however, safety scores were better than general knowledge related to epilepsy within this sample of

YPWE in the USA. Gaps in safety knowledge were also found by Pauschek et al. (2016). Safety precautions were known by half of participants, 54% were able to identify a specific precaution to prevent harm from seizures and 7% stated that non-adherence to safety precautions would result in new seizures. Smith et al. (2021) asked questions specifically related to safety practices; a small number of children believed that an object should be placed in the mouth of a person having a seizure.

Contraception in Epilepsy and Childbearing.

Eighty-five adolescent (aged 13-18) girls answered questions related to contraception and childbearing within epilepsy in a survey from the USA and achieved a mean correct response rate of 17.4%, which was poor (Agarwal et al., 2014). Also in the USA, young girls (aged 13-19) participated in focus groups (N=26) and surveys (N=114). The majority (71%) of survey respondents knew that antiepileptic medication could reduce contraception effectiveness, with focus group members making similar statements. Most of the survey (66%) and focus group noted that types of contraception can increase seizure activity, and 32% of survey responders noted that they could also reduce seizures. However, there was uncertainty amongst both survey respondents and those in focus-groups regarding the interactions between contraception and antiepileptic medication. For instance, 28% were unsure whether medication reduced the effectiveness of birth control, and 29% and 44% were unsure whether certain contraception increased or reduced seizures, respectively. Overall, it was concluded that the teenagers lacked appropriate information and had incomplete knowledge about contraception use within epilepsy (Manski & Dennis, 2014). Ryu et al. (2015) found that over 60% of their sample incorrectly answered a

question related to childbearing in epilepsy. Amongst girls aged 13-18 it was reported that the majority had not received information about contraception and pregnancy, and although girls aged 18-19 have received some information, they could not remember specifically what they had been told (Lewis & Noyes, 2013). Within the Lewis and Noyes' (2013) focus groups, four pregnant teenagers said that they could not accurately remember the information they were given on pregnancy. Taken together, the evidence suggests that YPWE do not have adequate knowledge about contraception and childbearing knowledge.

Desire for Further Information in YPWE and Nurses

Eight studies alluded to participants wanting more information.

Out of 306 school nurses in Greece, 99.3% believed that they needed to attend continued education programs on school health (Toli et al., 2013). Additionally, in a study of school nurses in Japan, 79.8% wanted to attend classes to learn about epilepsy (for example, first aid, fundamental knowledge about epilepsy, treatment and difficulties YPWE may face) and 79.8% said that they wanted to learn about epilepsy themselves (Terada et al., 2020). Another study from Japan noted that of the 285 home-healthcare nurses surveyed, the majority (87.7%) were interested in a workshop about epilepsy (Nishina & Yoshioka, 2018). Additionally, 91.5% of 213 clinical nurses surveyed wanted additional training in the field of epilepsy (Prabhu et al., 2021).

In a survey conducted in the USA, 56.4% of 13–18-year-olds wanted more information about epilepsy, although they did not allude to specific information needs (Agarwal et al., 2014). Another study in the USA found that both focus group and survey participants, aged 13-20, wanted more in depth and comprehensive counselling regarding contraception and wanted peer support. Most focus group and survey (52%) participants reported a desire to be told more about contraceptive issues for those with epilepsy (Manski & Dennis, 2014). In a study conducted in the UK, children described mixed views on receiving additional information, with most being content with their understanding and others wanting more information about epilepsy: “I think I would like to know it more. Like properly” (Harden et al., 2021, p.5). In another UK study, young people noted that they wished for verbal information to be supported by written information to aid their understanding (Lewis & Noyes, 2013).

Factors Linked to Knowledge

Variables significantly related to knowledge-level varied across studies. Within a study of clinical nurses from Turkey, it was noted that nurses’ level of education and income were significant predictors of knowledge. Notably, those with bachelor and associate degrees showed significantly superior knowledge when compared to college graduates. Additionally, those with lower income had significantly less knowledge than those with higher incomes. Additionally, there was a significant, positive correlation between knowledge and attitudes; increased knowledge was associated with increased attitude. Age, gender, marital status, working period, and experience of a family member with epilepsy were not significantly correlated with knowledge levels (Dayapoğlu & Tan, 2016). Conversely,

in a study of clinical nurses surveyed in Iran, nurses younger than 25 years of age had significantly higher levels of knowledge. Additionally, nurses that had a relative with epilepsy had significantly more knowledge about epilepsy compared to those without familial experience (Abbas et al. 2019). However, there were no significant differences in knowledge scores based on working period, sex, marital status, educational level, and income. Interestingly, amongst clinical nurses in Niger, it was found that nurses aged less than 30 years-old were significantly more likely to believe that epilepsy can be transmitted by breathing in gas emitted by a person having a seizure (Assadeck et al., 2020). Additionally, in a sample of school nurses in Japan, it was found that receiving information from medical institutions significantly improved school nurses' knowledge about their students with epilepsy (Terada et al., 2020). Nishina and Yoshioka (2018) found that increased experience of epilepsy in home-healthcare nurses resulted in a higher desire to attend epilepsy training.

When thinking about the variables that were linked to the knowledge of YPWE, significant predictors of 'high scorers' in YPWE in the USA included factors such as older age, Caucasian race compared to African American race, and employment of one caregiver in professional occupations (Agarwal et al., 2014). Participants in both Harden et al. (2021) and Lewis and Noyes' (2013) qualitative studies reported that medical jargon negatively impacted information exchange, with some children not understanding the information shared in appointments. Having a person-centred approach to information exchange, having information repeated to them and receiving written resources to support verbal information were all listed as potential facilitators to information exchange (Lewis & Noyes, 2013). A shared theme across the two qualitative studies was the notion that some young people were afraid

of hearing about epilepsy and reluctant to speak about seizures, which may have impacted knowledge levels. Regarding facilitators to knowledge acquisition, both studies highlighted the importance of parents. For example, some reported that having parents present in clinic appointments supported information acquisition, and parents were a primary source of information. A similar finding was reported by Manski and Dennis (2014), in which parents helped young people to understand information about contraception in epilepsy. However, some children felt silenced by adults, including parents and clinicians, in their appointment (Harden et al., 2021). Other facilitators to young people's knowledge included repeated information. Smith et al. (2021) found that 'transition readiness', or the preparedness of a child with epilepsy to adult services, was significantly positively correlated with adolescent and young adult knowledge ($r= 0.31$). That is, as transition readiness increased so did knowledge. Additionally, Ryu et al (2015) found that knowledge about epilepsy and perception of stigma were significantly related; interestingly, those with a 'very low' level of knowledge had significantly lower stigma score than those with a 'low' level of knowledge.

Discussion

Summary of The Main Results

This systematic review provides insight into studies, published from 2010 onwards, that have explored the level of knowledge about epilepsy in qualified nurses and YPWE across the globe. Where possible, it also evidenced the factors that impacted knowledge levels.

Nurses' Knowledge

It is difficult to draw a meaningful, overarching conclusion about nurses' epilepsy-related knowledge due to the heterogenous ways in which knowledge was assessed and operationalised. Despite these challenges, narrative synthesis highlighted gaps in nurses' knowledge across various domains, including: the aetiology of epilepsy; clinical manifestations; seizure management and safety practices. Deficits in knowledge existed in a variety of nursing roles although different gaps were seen in studies undertaken in different countries.

Notably, when asked, a percentage of nurses believed that epilepsy was a mental health disorder or caused by a mental health disorder. Although a minority held this inaccurate belief, it is still important to note as this was opined by a range of nurses, across various countries, and could result in further stigmatisation and reluctance to seek treatment (WHO, 2022).

Inaccurate, potentially dangerous beliefs about safety practices were held. Whilst this belief was held by a minority it is likely to have a detrimental impact on the care offered to people with epilepsy. Regarding treatment, less than half of the nurses surveyed in Harimanana et al. (2013)'s study in Laos PDR believed in modern medicine. Additionally, nurses in Iran, Niger, Egypt and India endorsed alternative/homeopathic treatment. These are all considered 'developing' or 'least developed' countries (United Nations, 2014). In many low- and middle-income countries, access to antiseizure medication is scarce (WHO, 2022) perhaps contributing to the endorsement of non-medical treatment, although there is currently

no evidence of this relationship. Internationally, there has been a focus on improving the wellbeing of people with epilepsy, including their access to effective treatment. The MhGAP (WHO, 2016) aimed to scale up services for mental, neurological, and substance use disorders within low-and middle-income countries. Regarding epilepsy, it advocated that all people with epilepsy should have access to treatment in poor-resourced countries, through training and educating clinicians and patients. Promisingly, it has been successfully implemented in some low-income countries (Dos Santos et al., 2019). This may help to dispel some of these inaccurate beliefs. However, it should be noted that other nursing studies included in this review from Japan, Turkey, and Greece did not examine clinicians' beliefs about 'alternative' treatment. Therefore, it is also possible that these beliefs are held by others in developed countries.

There were mixed findings regarding the factors linked to nurses' knowledge. For example, level of education and income was associated with increased knowledge in Turkey (Dayapoğlu & Tan, 2016) but not Iran (Abbas et al., 2019). Age was associated with knowledge in Niger, with significantly more nurses aged under 30-years-of-age believing that epilepsy is caused by breathing in gas emitted during 'crisis' (Assadek et al., 2020) and Iran, with knowledge being significantly higher in nurses under 25-years-of-age (Abbas et al., 2019). Age was not significantly associated with knowledge in Turkey. Additionally, having a relative with epilepsy was not associated with increased knowledge amongst nurses in Turkey (Dayapoğlu & Tan, 2016) but was amongst nurses in Iran (Abbas et al., 2019).

In a sample of school nurses in Japan, receiving additional information about epilepsy improved knowledge (Terada et al., 2020). Although this is beyond the scope of the review, this suggests that receiving additional information can improve clinical knowledge and supports the notion that additional education should be offered. There was evidence that nurses from various countries wanted more information and education about epilepsy. Indeed, within the four studies that asked, between 79.8 - 99.3% wanted further education or training about epilepsy (Nishina & Yoshioka, 2018; Terada et al., 2020; Toli et al., 2013; Prabhu et al., 2021). This highlights that the nurses themselves are aware of their need for further information.

Young People's Knowledge

The present review found that there were deficits in knowledge amongst YPWE. Three studies across the USA, UK, and Korea deemed overall knowledge as poor (Agarwal et al., 2014; Lewis & Noyes, 2013; Ryu et al., 2015). When one study deemed knowledge to be acceptable in the context of daily life, gaps were still evident (Harden et al., 2021). Specific knowledge gaps were evident in all studies.

There were inaccurate beliefs about the aetiology of epilepsy amongst participants. For example, 60% of adolescents believed it was caused by a mental health condition in a study in Korea (Ryu et al., 2015) and 18% in a USA study (Smith et al., 2021). Like nurses, there was a paucity of studies that asked about the knowledge regarding mental health in epilepsy. Knowledge about medication was also investigated and mixed results were found. Regarding safety practices, there were inaccurate and potentially dangerous beliefs held by YPWE across the three

studies (Agarwal et al., 2014; Pauschek et al., 2016; Smith et al., 2021). Across all studies that investigated contraception and childbearing, it was found that young women had inadequate levels of knowledge. This was commensurate with the systematic review previously published by Lewis et al. (2010).

Within two studies (Agarwal et al., 2014; Manski & Dennis, 2014) between 52-56.4% of YPWE wanted additional information about epilepsy-related topics. However, the desire for more information was more mixed amongst YPWE when compared to nurses. For example, in one study, whilst some wanted additional information about epilepsy, most described being content with their knowledge, despite gaps being evident (Harden et al. 2021). A previous systematic review proposed that children may be reluctant to ask for more information in case it resulted in negative consequences, such as risk of losing independence if they are informed that they cannot participate in activities (Lewis et al., 2010).

Within a study from the USA factors such as older age, race, and occupation of parents influenced knowledge amongst YPWE (Agarwal et al., 2014). Within two UK-based studies, medical jargon hindered knowledge acquisition. Some YPWE felt that parents helped them to understand information, although not all wanted parents to be present. Accessible, person-centred, written information was also listed as a positive influence on YPWE's knowledge (Harden et al., 2021; Lewis & Noyes, 2013). Current UK epilepsy guidelines highlight the importance of tailored, person-centred information for YWPE and their families (NICE, 2022); this review highlights that this approach is something that is desired. The readiness of a child to transition to

adult services and stigma also influenced knowledge levels (Ryu et al., 2015; Smith et al., 2021).

Overall Completeness and Applicability of Evidence

Overall, the current review identified studies published from 2010 onwards, that aimed to investigate knowledge amongst qualified nurses and YPWE. Eleven studies reported the variables that were linked with knowledge-levels. Therefore, the included studies were relevant to the review's research questions.

Studies investigating nurses' knowledge were conducted over a range of high- and low-income countries, highlighting that the level of epilepsy-knowledge is considered a research worthy topic worldwide. A variety of nurses were included, suggesting that that knowledge deficits are not limited to specific nursing roles. Interestingly, none of the studies surveyed ESNs. This is not entirely unexpected as ESNs are not a universal role (Prevos-Morgant et al., 2019). However, studies included in this review could not provide a comprehensive overview of the levels of knowledge amongst ESNs, as they likely have higher levels of knowledge compared to non-specialist nurses.

Qualitative studies, as well as quantitative designs, investigated YPWE's knowledge which allowed for more in-depth insight (Hall & Harvey, 2018). However, all qualitative studies came from high-income countries. People with epilepsy from lower-income countries are more likely to face discrimination, stigma and ostracism from the community (Newton & Garcia, 2012); all of which could impact access to

information and knowledge. Therefore, investigating knowledge levels in this population would be beneficial to give insight into this already marginalised group.

Amongst YPWE and nurses, the studies investigated a range of areas of knowledge. However, the lack of investigation into knowledge regarding psychological issues in epilepsy was notable. The International League Against Epilepsy's survey of healthcare professionals' management of depression and anxiety in epilepsy highlighted that more than half of the professionals felt inadequately resourced to manage depression and anxiety (Gandy et al., 2021). Knowledge about mental health comorbidities has been described as "lacking" within epileptologists (England et al., 2012). It is possible that these gaps in knowledge also exist amongst nurses. Considering that people with epilepsy, and YPWE, are at a significantly increased risk of mental health conditions (Hargreaves et al., 2021), it is surprising that knowledge about mental health was not investigated comprehensively. This is an area that warrants further research.

Measurement of Knowledge

This review identified studies that were in-line with the research question and applicable to people in various countries. However, the heterogenous ways in which knowledge was measured across studies made it difficult to make comparisons and draw meaningful conclusions. This limited the ability to synthesise the data and answer the review questions in a comprehensive way to produce conclusions for clinical practice. The surveys were mostly bespoke, investigated different areas of knowledge and used a range of question formats. The way in which data was reported

also varied, with some giving individual items scores or overall judgements. When overall knowledge levels were reported, they were often based on subjective, arbitrary criteria rather than objective standardisations.

Studies that investigated the knowledge of nurses in other contexts have faced similar challenges when trying to systematically synthesise data (Evrpidou et al., 2019; Mpouzika et al., 2021). Within epilepsy literature, similar conclusions were found when trying to investigate the epilepsy-knowledge of teachers (Jones et al., 2018).

Quality of the Evidence

In addition to heterogeneous measures, most quantitative studies utilised instruments that were not psychometrically sound. As valid and reliable measures are a prerequisite to the integrity of the results, caution should be taken when interpreting the conclusions. Additionally, convenience sampling was employed which meant that there could have been systematic bias in the samples, limiting the validity of findings (Ritchie et al., 2013). Most of the mixed-methods and quantitative studies had adequate response-rates and the majority (56.3%) had a sample that was representative of the target population. All used a justified analytic approach. However, the overall quality of the cross-sectional and mixed methods studies was poor.

The qualitative studies were good quality. However, one failed to consider the impact of reflexivity, an integral part of rigorous qualitative research (Corlett &

Mavin, 2018). However, reflexivity is often omitted from published reports due to restrictions in word-limits rather than lack of completion (Busso & Leonardsen, 2019)

Notably, the quality of the qualitative elements of the mixed-methods designs were deemed to be of considerably higher quality than their quantitative counterparts. This suggests that high-quality quantitative studies are lacking in this area, although it is possible that knowledge levels and needs can be more comprehensively measured using qualitative methods.

Potential Biases in the Review Process

A major strength of the review was the mixed methods approach which allowed for a more complete insight into knowledge compared to single method reviews (Stern et al., 2020). However, the lack of clear guidance and varied approaches to synthesis data added additional complexities (Hong et al., 2017). An additional strength was the methodological rigour; a second, independent reviewer was consulted throughout the research process including study selection, which supported precision (Stoll et al., 2019); data extraction and quality analysis. This minimised error, reduced bias, and improved the reliability of the review.

Only two databases were utilised, and although this has been justified in literature (Vassar et al., 2017) it is possible that relevant papers may have been missed. To mitigate this risk, forward and backward citation searching was used which yielded four additional studies. Although this is a small number, it could be suggestive of inadequacies in the search terms used. However, a librarian was

consulted in the development of search terms, thus limiting this risk. The current review only included studies published in English. Dissertations and theses were excluded. This could have resulted in publication bias and meant that important data was omitted from the review (Paez, 2017). Another limitation was the fact that only qualified nurses were included and therefore the knowledge levels of student nurses were not reviewed. Student nurses were excluded as they may not have received information or training on epilepsy at the point of data collection, therefore, knowledge levels may not be reflective of nurses post-training.

As a previous systematic review had examined literature published prior to 2010 (Lewis et al., 2010), only papers published from 01.01.2010 onwards were included. However, Lewis et al.'s (2010) review focused more heavily on information needs and information exchange rather than the current knowledge levels of YPWE. Therefore, it is possible that this may have led to relevant papers being missed. This is noted as a limitation of the current review.

The MMAT quality appraisal tool provides item checklists for researchers to support their decisions when rating the quality of studies. However, a limitation of the MMAT is that these items can be difficult to rate and unclear to judge, leaving them open to interpretation (Hong et al., 2018a). Resultantly, the primary researcher made subjective judgements on aspects of the quality rating, such as the appropriateness of measures and sample representativeness, when appraising the studies. It is possible that this impacted the replicability of the ratings made. To maximise the validity of ratings the primary researcher aimed to be consistent in their decisions across all papers. This is an issue for the MMAT as well as other quality assessment tools that

require a degree of subjectivity and are influenced by the researcher's knowledge and skill level (Ma et al., 2020).

Agreements With Existing Literature

Nurses

This is believed to be the first study to investigate the epilepsy-knowledge of nurses; therefore, it is difficult to render comparisons. However, in Mahendran et al.'s (2017) systematic review of unmet needs in adults and YPWE from around the world, participants believed that clinicians' lacked knowledge about epilepsy-specific topics. The current review supports the notion that nurses in this review had sufficient gaps across all areas of knowledge to warrant concern. The current findings support the conclusions drawn by others that aimed to investigate epilepsy-knowledge levels of teachers. Deficits in knowledge exist but results are limited by poor research design and varied instruments. It supports the notion that there would be benefit in having a single, psychometrically sound instrument to investigate knowledge (Jones et al., 2018). This would allow for a valid, consistent reporting of results that could result in more meaningful, comparisons across studies and countries (Evrpidou et al., 2019); thus, providing more pertinent answers to the review questions.

Young People

The current review did not address the same review question as Lewis et al. (2010), as it was more focused on current knowledge level of YPWE, rather than investigating the information-exchange experiences. However, the following propositions were supported in both reviews: parents can support knowledge exchange (Harden et al., 2021; Lewis & Noyes, 2013; Manski and Dennis; 2014); young women are not receiving or remembering women's-health advice (Agarwal et al., 2014; Lewis & Noyes, 2013; Manski & Dennis, 2014; Ryu et al., 2015); young people need more practical advice about lifestyle management, including seizure management (Smith et al., 2021; Woltermann et al., 2020).

Clinical Implications and Future Research

Given the existing gaps in knowledge, inaccurate beliefs, and the self-reported desire for more information, there would be merit in continuing to educate YPWE and nurses around the world about epilepsy. Although beyond the scope of the review, psychoeducation interventions have proven promising in improving knowledge in YPWE and their caregivers (Kaye, 2021; Corrigan et al., 2016) and this review supports the need for such interventions. Additionally, the findings further support the use of international programmes and guidelines, such as the mhGAP (WHO, 2016) and NICE (2022) guidelines, that emphasise the importance of educating and training clinicians and patients about epilepsy.

As previously noted, further research investigating the knowledge levels of YPWE in low-and middle-income countries is needed. For both YPWE and nurses, research investigating the current knowledge levels regarding mental health in

epilepsy is needed to shed light on this relatively unknown area. The development of a single research tool that examines knowledge, that is psychometrically sound and culturally sensitive, would be beneficial to allow for more meaningful comparisons to be made across countries and studies.

Conclusions

The current study provided a systematic overview of the literature that investigated YPWE and nurses' epilepsy-knowledge. Overall, areas of knowledge were lacking amongst nurses and YPWE, and inaccurate beliefs were documented in all studies across the globe. Several factors were found to influence knowledge-levels. However, methodological limitations, such as heterogenous, unvalidated measures, arbitrary categorisations of data, and potential sampling bias, make it difficult to draw meaningful conclusions and comparisons across studies. The development of a single, validated measure to assess knowledge would be beneficial.

Paper 2.

**Mental Health Information Needs in Epilepsy – Insight From Young People
With Epilepsy and Parents**

Empirical Project

Abstract

Background: Young people with epilepsy (YPWE) have an increased risk of mental health difficulties; identification, diagnosis and treatment are suboptimal. Sharing information with YPWE and their parents can help them to make informed decisions, advocate for treatment, and can enhance empowerment. Clinical guidelines note that YPWE and their parents should be given information about psychological issues. However, there is a paucity of research investigating the mental health information needs of YPWE and their caregivers. The current study aimed to investigate the information needs and preferences of YPWE and their caregivers. Additionally, it aimed to investigate the disparities between the current and desired provision of information, as well as ways to address these disparities.

Methods: Parents (N=8) and YPWE (N=3) participated in semi-structured interviews.

Results: Through Reflexive Thematic Analysis, five themes were established:

1. 'Responsibility Is Placed on Parents and Young People'. Many parents felt responsible for getting information and wanted more support.
2. 'Information Provision Is Inadequate'. Many parents and YPWE had inadequate knowledge about mental health in epilepsy and had received poor mental health support. Some believed this was due to poorly integrated services. Many wanted more holistic, integrated support.

3. 'The Role of Care Providers'. The importance of positive relationships with professionals and good interpersonal skills were highlighted. The preferred role of professionals was also discussed.
4. 'What Is the Right Amount of Information?'. The 'right amount' of information varied across participants.
5. 'Information Should Be Tailored to Individual Needs' was expressed by many.

Conclusion: Within the sample, mental health information needs were not being met and person-centred, holistic approaches were not frequently utilised. Information regarding mental health was scarce. Parents and YPWE provided various suggestions regarding the content, timing, and delivery of mental health information. The desire for information to be tailored to individual needs was deemed important.

Introduction

Mental Health Difficulties in People with Epilepsy

Epilepsy is characterised by the presence of recurrent seizures, caused by abnormal electrical activity in the brain (Corrigan et al., 2016). Epilepsy is one of the most common neurological conditions in children and young people, with an estimated prevalence of 0.5-1% worldwide (Aaberg et al., 2017). Young people with epilepsy (YPWE) have an increased risk of developing mental health difficulties when compared to the general population and those with other physical-health conditions (Hargreaves et al., 2021; Salpekar & Dunn, 2007). For example, a meta-analysis by Scott et al. (2020), reported the overall pooled prevalence of anxiety and depression was 18.9% and 13.5%, respectively, amongst YPWE. When compared to ‘healthy’ controls, rates of depression and anxiety were significantly higher. This may be due to neuro-epileptic, psychosocial and medication factors (Antonak & Livneh, 1992). Mental health difficulties have a significant impact on YPWE’s quality of life as well as the wellbeing of their family (Cianchetti et al., 2018; Healy et al., 2020).

There are effective, evidence-based psychological interventions for this population. However, they are often not implemented due to obstacles at clinician, service and organisational levels (Shafran et al., 2020). For example, mental health problems are often not identified and are underdiagnosed (Corrigan et al., 2016). Additionally, YPWE may not be referred for treatment or accepted by services they are referred to, and evidence-based interventions may not be provided if the referral is

accepted. There is a lack of mental health provision for YPWE and mental health support is poorly integrated into services compared to other paediatric settings, such as diabetes care (Hargreaves et al., 2021).

Why Is It Important to Know the Information Needs of Young People with Epilepsy and Their Caregivers?

Information sharing and knowledge is a central concept for the empowerment of young people and their families, including those with epilepsy (Chong et al., 2016; D'Alessandro & Dosa, 2001). Empowerment is recognised as a fundamental principle of patient care. Empowerment theory defines empowerment as a process through which individuals lacking an equal share of resources gain greater access to and control over those resources (Perkins & Zimmerman, 1995). From a patient-provider perspective, empowerment can be considered as a process in which knowledge, values and power are communicated and shared (Aujoulat et al., 2007). The World Health Organisation (WHO) have advocated the importance of enhancing patient empowerment to improve care and patient health (Aymé et al., 2008). One way empowerment is achieved is through the delivery of personalised care, which can be provided once individual information needs are understood. The National Health Service's (NHS) Long Term Plan outlines the need for personalised care tailored to individual need, placing patient autonomy at the forefront. This personalised care aims to connect people to information relating to their individual needs (Sanderson et al., 2019). Therefore, identifying service-user information needs is the first step in providing personalised care and empowerment.

Sharing information related to the presentation of health conditions, as well as treatment options and their value, can empower patients to improve their health outcomes (Serrano-Gil & Jacob, 2010). For epilepsy, sharing information with patients and their families allows informed decision making about care and enables them to be advocates for their own mental health treatment (Kobau et al., 2019). Many YPWE believed that receiving education about their condition empowered them to gain more independence and self-efficacy (Lewis et al., 2013). Knowledge can also improve self-esteem, coping and mood amongst adolescents (Baker et al., 2005).

Outstanding Information Needs in Epilepsy

Despite the benefits of information sharing, there are unmet information needs and low levels of knowledge in YPWE (Agarwal et al. 2014; Lewis et al., 2010; Manski & Dennis, 2014; Ryu et al., 2015). In their systematic review of unmet health needs, Mahendran et al. (2017) found twice as many papers commenting on the unmet mental health needs of people with epilepsy compared to unmet physical health needs. Parents of YPWE also have unmet information needs. This can impede on their access to resources, mental health and capacity to cope (Nevin et al., 2020). The findings from paper 1 suggest there is missing knowledge about epilepsy and epilepsy-related factors in YPWE and some, although not all, wanted more information. However, knowledge regarding mental health was limited within these studies; therefore, the participants' knowledge and information needs were largely unknown.

The National Institute of Clinical Excellence (NICE) have updated their guidelines regarding the diagnosis and management of epilepsy in children and young people (NICE, 2022). The guidance reports gaps in the information available for YPWE and their families, with some feeling that information is withheld (NICE, 2022).

Additionally, literature has suggested that YPWE and their parents wish for more information regarding a range of epilepsy-related topics (Agarwal et al., 2014; Lewis et al., 2010; Manski & Dennis, 2014). Parents noted a particular need for information about emotional support, although this mostly related to parental mental health (Nevin et al., 2020). Henning et al. (2019) conducted a survey with 1182 adults with epilepsy and found that over 90% wanted information on cognitive/psychiatric issues and, of those that did receive this information, less than 50% rated this as satisfactory. Research related to the *mental health* information needs of YPWE and their parents is limited.

Timely access to mental health treatment requires YPWE and their families to have knowledge of the signs and symptoms of mental health problems and the available services. Therefore, access to mental health information is pivotal. However, YPWE and their families are often not informed of the increased risk of mental health issues or the support available. A systematic review highlighted that parents experienced difficulty accessing information about epilepsy and unmet needs were associated with poor psychosocial outcomes and reduced satisfaction with healthcare services (Nevin et al., 2020).

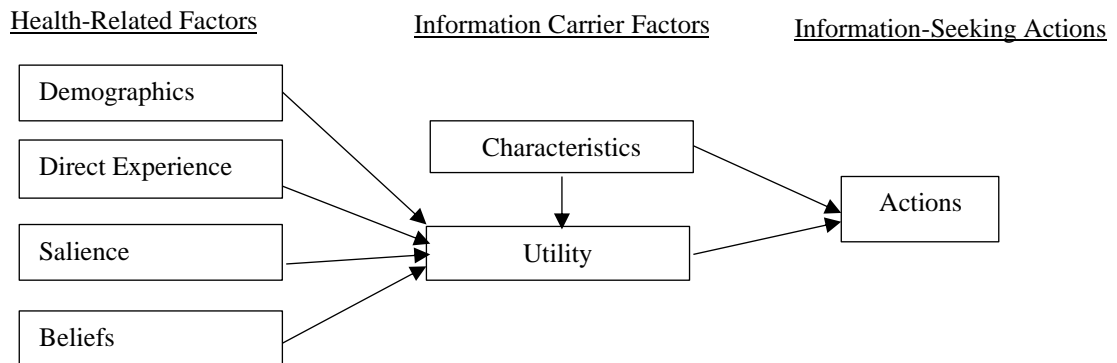
Current Guidelines and Practice Regarding Information Sharing in Epilepsy

The NICE (2022) guidelines have noted that YPWE and their families should be given information regarding psychological issues. However, they do not give recommendations on *what* information should be shared and *how* this should be communicated, in relation to mental health in epilepsy. There is a need to understand how best to support parents, and young people, regarding their informational needs (Young Epilepsy, 2017). The information that individuals need, and how they acquire it, varies according to individual factors (Kendall et al., 2004). For example, some need information in different formats or during different periods of time.

The Comprehensive Model of Information Seeking (CMIS) by Johnson & Meischke (1993) explains factors related to information seeking and has been applied to different health contexts (Basnyat et al., 2018). The CMIS suggests that personal health-related factors such as demographics, previous experiences, beliefs and how ‘salient’ an issue is, influence the ‘Carrier Utility’: whether the information meets the need of the individual, is relevant and appropriate. ‘Carrier Characteristics’ involve the direct evaluation of information (e.g., is the information source credible and comprehensive?) and influence ‘Carrier Utility’. Whereas health-related factors influence information need and can predispose individuals to search for information, how they search is informed by information carrier factors. These factors in turn affect an individual’s information seeking actions (Johnson & Meischke., 1993; Johnson et al., 1995), as shown in Figure 2.

Figure 2

Comprehensive Model of Information Seeking



Note. Comprehensive Model of Information Seeking. From “Cancer-Related Information Seeking Applied to Magazines”, by J. D. Johnson and H. Meischke, 1993, *Human Communication Research*, 19(3), p. 345.

To provide relevant information, one should understand the health-related factors and information carrier factors of the individual, as these drive an individual’s information needs and impact how they search for information – or avoid it (Case et al., 2005). Understanding these factors could help to facilitate the information seeking process and ensure the provision of individualised, tailored information. Currently, these information needs are unknown in relation to mental health.

More generally, evidence has shown there are discrepancies between the information people with epilepsy/their families *want* and what they *receive*, with perceived needs being defined by professionals rather than patients (Couldridge et al.,

2001; Kendall et al., 2004). There is often an untested assumption that all information is useful to share which is not always the case (Kendall et al., 2004). For example, parents do not want to be overwhelmed with information. Some service-users felt that information was hierarchal and did not meet their needs (Nevin et al., 2020; Vona et al., 2009). Shafran et al. (2020) noted that while many families wanted to receive information, including mental health information, others found it overwhelming. This was also seen in YPWE, with some expressing a desire for more information but others being hesitant (Harden et al., 2021). Wu et al., (2008) conducted focus groups with parents of epileptic children and found that some avoided mental health services and felt disturbed when hearing their child may be at increased risk of mood difficulties, whereas others perceived these services as useful. Again, this highlighted the differing needs of information amongst parents.

Strzelczyk et al., (2016) investigated the attitudes of physicians regarding counselling people with epilepsy about associated risk factors, including suicidal ideation. They found only 3.3% of physicians discussed the increased risk of suicide ideation with all their patients. There are limited studies investigating clinician's preferences on disclosing information about mental health risks in epilepsy. However, epilepsy clinicians often lack resources, knowledge, and expertise regarding mental health services and subsequently may not know what information to communicate with service-users (Smith et al., 2007).

The Current Study

Whilst research has investigated the *general* information needs of YPWE and their families, there is a paucity of research exploring their information needs related to mental health. Some studies reported on the psychological information needs of parents and young people, however as it was not the primary aim they only provided brief information on this vast topic. YPWE and their caregivers should be counselled on the psychological risk factors associated with epilepsy (NICE, 2022). However, this is not always implemented. Additionally, there is a need to understand people's preferences regarding the content, timing, and format of this information as there is a little evidence exploring this. To provide information that meets the needs of service-users and avoid disempowerment, further investigation into content, timing, and format preferences for YPWE is critical. To the authors knowledge, no study has specifically investigated the mental health information needs of YPWE and their caregivers and this novel research hoped to provide comprehensive insight. The current study aimed to identify the information needs and preferences regarding mental health and epilepsy for young people with epilepsy and their families.

Research questions

1. What are the information needs and preferences of children or young people with epilepsy and their caregivers, regarding mental health and epilepsy?
2. What are the disparities between current information provision and information needs and preferences, regarding mental health and epilepsy, and how can we address these gaps?

Method

Participants

The final sample consisted of three young people with a diagnosis of epilepsy and eight parents of children with epilepsy. Participant characteristics are shown in Table 4 and 5. Participant dyads are displayed in Table 6.

Parents of YPWE were eligible if they: (1) cared for a young person, aged 3-18 years, who had a diagnosis of epilepsy, (2) could speak and read English, and (3) were not at risk of harm to self or others. Young people were eligible if they: (1) had a diagnosis of epilepsy, (2) were aged between 11-18 years of age, (3) could speak and read English, and (4) were not at risk of harm to self or others. This age range was selected as children aged 11 years and upwards can articulate and openly discuss mental health (Roose & John, 2003).

The current sample size was deemed appropriate according to Braun and Clarke's (2013) guidance, which suggests that 10-20 participants is sufficient for a thematic analysis of individual interviews. Within the field of epilepsy research, Laybourne et al., (2015) utilised thematic analysis to analyse data from semi-structured interviews from 10 participants and were able to provide a detailed account of participants views and successfully meet the study's aims. Therefore, it was hoped that recruiting a similar number of participants would allow for sufficient data to meet the research aims.

YPWE and their parents were recruited through charities (Young Epilepsy, Epilepsy Research UK, Epilepsy Scotland, Well Child, Epilepsy Action) and social media (Twitter and Facebook). Charities were contacted via email, and they were given information regarding the research project and a request to advertise through their mailing-list or website. A template advertisement, which could be sent to potential participants, was provided to the charities (Appendix B). The lead researcher attended the Epilepsy Society Youth Group to discuss the research with young people.

Potential participants were invited to register their interest by emailing the lead researcher. Once participants registered their interest, they were sent an information sheet and consent form. Once this was completed, participants were asked to complete a risk assessment, demographics form and then sent an invitation to attend the online interview.

Ethical approval for this project was granted by Royal Holloway University of London Ethics Committee (REC project ID 2517) (Appendix C). Ethical approval was not sought from the Health and Research Authority within the NHS as all participants were recruited through charities.

Table 4.***Parent Demographics***

ID	Gender	Age	Ethnicity	Employment Status	Child's Gender	Child's Age at Participation	Child's Age of Diagnosis	Has their child had, or currently have, any difficulties with their emotion or behaviour?	Has their child received support for emotional or behavioural difficulties?	Does their child have a diagnosed ID, developmental delay, special needs, or problems at school?	What professionals do they see regularly?
P1	Female	45-54	British Indian	Part-time employment	Male	12	11	Yes	No.	No.	Paediatrician Neurologist Epilepsy Nurse GP
P2	Female	45-54	White British	Carer	Male	15	12	Yes	Yes.	Yes.	Epilepsy Nurse
P3	Female	55-64	White British	Full-time employment	Female	16	6	Yes	Yes (at school).	Yes.	-
P4	Female	45-54	White British	Carer	Male	13	3	No	Yes.	Yes.	Paediatrician Neurologist Epilepsy Nurse
P5	Female	45-54	White British	Full-time employment	Male	12	5	Yes	Yes.	Yes.	Paediatrician Neurologist Epilepsy Nurse
P6	Male	45-54	White	Full-time employment	Male	12	5	Yes	Yes.	Yes.	Paediatrician Neurologist

											Epilepsy Nurse	
P7	Female	35-44	White British	Carer		Male	4	3	Don't know (child non-verbal)	No.	Yes.	Paediatrician
P8	Female	35-44	Prefer not to answer	Part-time employment		Male	13	6	Yes.	Yes.	Yes.	Neurologist Epilepsy Nurse GP

Note. ID = intellectual disability.

Table 5.

Young People with Epilepsy Demographics.

ID	Gender	Age at Participation	Ethnicity	Age of Diagnosis	Other medical/physical problems?	Have they had, or currently have, any difficulties with their emotion or behaviour?	Have they received support for emotional or behavioural difficulties?
YP1	Male	12	British Indian	11	No	Yes	No.
YP2	Female	13	White British	4	No	Yes	Yes.
YP3	Male	13	Prefer not to answer	6	No	Yes	Yes.

Table 6.

Participant Dyads

Pair	Relationship
P1 and YP1	Parent and Child.
P5 and P6	Partners.
P8 and YP3	Parent and Child.

Materials

Participant information sheets, consent forms, demographic forms and recruitment advertisements were developed by the lead researcher. Recruitment advertisements (Appendix D) were reviewed by Patient and Public Involvement (PPI) group members.

Three online participant information sheets were developed: one for young people; one for parents on behalf of young people under the age of 16; and one for parents (Appendix E). Online consent forms were attached to the end of the information sheets. Three consent forms were developed: one for parents/caregivers; one for young people over the age of 16; and a consent form for parents to complete on behalf of young people under the age of 16, as well as an assent form for the young person (appendix F).

The demographics form for parents (appendix G) asked for a range of participant characteristics and included questions about their child with epilepsy. Young people were also asked to complete a demographics form (appendix H). Participants were then screened for risk and excluded if significant risk was identified. Young people were asked to complete the Strength and Difficulties Questionnaire (SDQ) (Goodman, 1997). The SDQ is a behavioural screening questionnaire for young people that examines emotional symptoms, conduct problems, hyperactivity/inattention, peer relationships and prosocial behaviour. It was deemed to have satisfactory reliability and validity (Goodman, 2001). Additionally, it has been used in epilepsy research (Bennett et al., 2021). Parents were asked to complete the Patient Health Questionnaire-9 (PHQ-9) (Kroenke et al., 2001), a measure of depression in adults. The PHQ-9 is commonly used within research and is deemed to have high internal reliability and criterion validity (Kroenke et al., 2010). If a participant scored higher than 0 on question 9 (“thoughts of being better off dead or hurting yourself”), a member of the research team would conduct a full risk assessment.

Initially, focus groups were considered to assess participants’ views as group members can feel safer with others who have had a similar experience. This could reduce power differentials and facilitate information sharing (Morgan & Krueger, 1993). However, due to difficulties with recruitment it was decided that semi-structured interviews with participants would be more appropriate. Within epilepsy research, semi-structured interviews have been considered as an effective way of gathering individual’s perspectives on a range of topics (Rapport et al., 2015). Additionally, they are deemed appropriate for thematic analysis and allow researchers

to consider the responses to questions as well as any changes in perspective during the interview (Rapport et al., 2015).

The interview schedule was created specifically for this project and reflected the aims of the study (Appendix I). It covered issues such as previous experience of receiving mental health information, information preferences and needs. It was developed after consultation with the literature on epilepsy and information seeking behaviour. The interview questions also drew on the CMIS (Johnson et al., 1995). Specific questions were designed to reflect the antecedents within the model. For instance, asking “*What is your experience of receiving information for your child with epilepsy?*” aimed to highlight an individual’s experience regarding mental health information. It was hoped that the interview schedule would ascertain participant’s information needs as well as highlight factors that influenced their current information seeking behaviour and preferences. The schedule included open-ended questions as well as specific probes. The schedule was intended to be used flexibly to allow participants to express their own views in a personally meaningful way (DeJonckheere & Vaughn, 2019).

The interview schedule was reviewed by the PPI group. In total, three parents of children with epilepsy reviewed the schedule and amendments were made in line with their recommendations. For example, adaptations were made to the language used in the interview to improve accessibility. Additionally, the PPI group highlighted that participants may not be aware of the association between mental health issues and epilepsy. Resultantly, an additional question ascertaining participant’s existing knowledge of mental health and epilepsy was added.

Procedure

All interviews were conducted by the primary researcher over 'Zoom', a video calling platform. Before commencing the interview, the interview process was explained to participants. At the end of the interview participants were thanked for their time and informed that results would be shared with them at the end of the study. There was also a chance for them to ask any questions or raise any concerns.

All participants were interviewed once, and each interview lasted between 38-120 minutes. The audio recordings of the interviews were stored on a password-protected computer and deleted as soon as verbatim transcription took place.

Data Analysis

Qualitative data was analysed using Reflexive Thematic Analysis (RTA), as outlined by Braun and Clarke (2020a). RTA has been described as a theoretically flexible approach to qualitative data analysis that makes sense of patterns or 'themes' across a dataset (Braun & Clarke, 2012). This framework was deemed appropriate as it aligned with the researcher's critical-realist ontological approach and allowed for the exploration of participant's subjective experience (Braun & Clark, 2020b). Semantic and latent coding was utilised. Semantic coding aimed to reflect the explicit content that was communicated by the participant, whereas latent coding was used to identify underlying meanings or concepts of the data, where appropriate. Analysis was mostly inductive and open-coded; however, a degree of deductive analysis was used to ensure that the inductive codes and subsequent themes were aligned with, and meaningful to, the research questions (Byrne, 2021).

The current study investigated a novel, poorly understood topic and it was decided that coding would be iterative and exploratory rather than requiring a codebook or frame (Braun & Clarke, 2019). Therefore, a predominantly inductive method was chosen over a coding reliability approach. Interpretive Phenomenological Analysis (IPA) was not chosen as the current project aimed to identify themes *across* the dataset, rather than an emphasis on individual cases (Braun & Clarke, 2020b). Additionally, our sample would likely be heterogenous which was less in keeping with IPA assumptions (Smith & Shinebourne, 2012). Grounded theory was rejected as the researcher wished to gather the varied and diverse views from participants, rather than obtaining a central, core ‘category’ that connects the data to derive a theory (Chun Tie et al., 2019). As the research questions were not primarily oriented to the effects of language, discourse analysis was not utilised (Braun & Clarke, 2020b). The entire dataset was analysed according to Braun and Clarke’s (2006; 2020a) stages:

1. Data familiarisation was achieved by actively listening to each interview prior to transcription. Transcription was completed manually, and the transcripts were read multiple times to allow the researcher to immerse themselves in the data. Familiarisation annotations were then completed and potentially relevant passages were noted.
2. Codes were then generated from the entire dataset. This resulted in interpretive labels for sections of the data that were relevant to the research questions.

Appendix J shows an example of the coding process.

3. Codes that shared a similar underlying concept were aggregated to reflect broader patterns of meaning. From this, potential themes were generated.
4. The candidate themes were reviewed against individual data items and codes to ensure homogeneity within the theme. Themes were also reviewed against the dataset in its entirety to ensure an appropriate interpretation of the data and heterogeneity among themes (Byrne, 2021).
5. Themes were further refined and reviewed. Clear definitions of the themes were developed. The ‘story’ that each theme conveyed was considered and it was ensured that the themes collectively provided a ‘story’ that was consistent with the data (Braun & Clarke, 2006).
6. A thematic map was created. This provided a visual representation of the themes and subthemes (Braun & Clarke, 2021). The report was written and extracts of the data presented to reflect each theme.

Credibility Checks

Themes do not exist as separate entities from researchers, instead they are generated through a process that is mediated by various factors that the researcher brings (Braun & Clarke, 2020b). Resultantly, there can be inconsistencies in the themes created from the data. To establish ‘trustworthiness’ of the research, Lincoln and Guba’s (1985) criteria of credibility was followed, which has been recommended within epilepsy research (Rapport et al., 2015). To achieve ‘Credibility’ and ‘Dependability’ the methodological process, as described previously, was adhered to and the primary researcher’s thoughts were documented in a reflective journal throughout the project. Contextual information, such as details of the sample and the

recruitment process, were provided to achieve ‘Transferability’. This refers to the notion that findings from a study can be seen as an example within a broader group context. ‘Confirmability’ is the extent to which the research’s conclusions reflect participant’s data rather than merely the researcher assumptions (Rapport et al., 2015). This was achieved through respondent validation. Following each interview, a summary of the main ideas was sent to participants for them to evaluate the accuracy (Appendix K). To reduce bias, codes and themes were checked with a second researcher.

Reflexivity

The first author was a British, 27-year-old female Trainee Clinical Psychologist that had direct experience of working with adults with epilepsy within a Neuropsychological service. The researcher’s perspective of receiving information from Healthcare Professionals (HCPs) had been mostly positive. Therefore, care was taken to ‘bracket’ the researcher’s views to mitigate the effect of preconceptions on the research process (Fischer, 2009). Supervision and a reflective journal (Appendix L) allowed the researcher to better consider how their constructs and assumptions influenced the research process. The researcher’s dual role as a clinician and researcher was also considered, as well as the power dynamics this may bring. To improve rapport and reduce power imbalances, participants were reminded there was no ‘right or wrong’ answer and they were considered the expert in their experience.

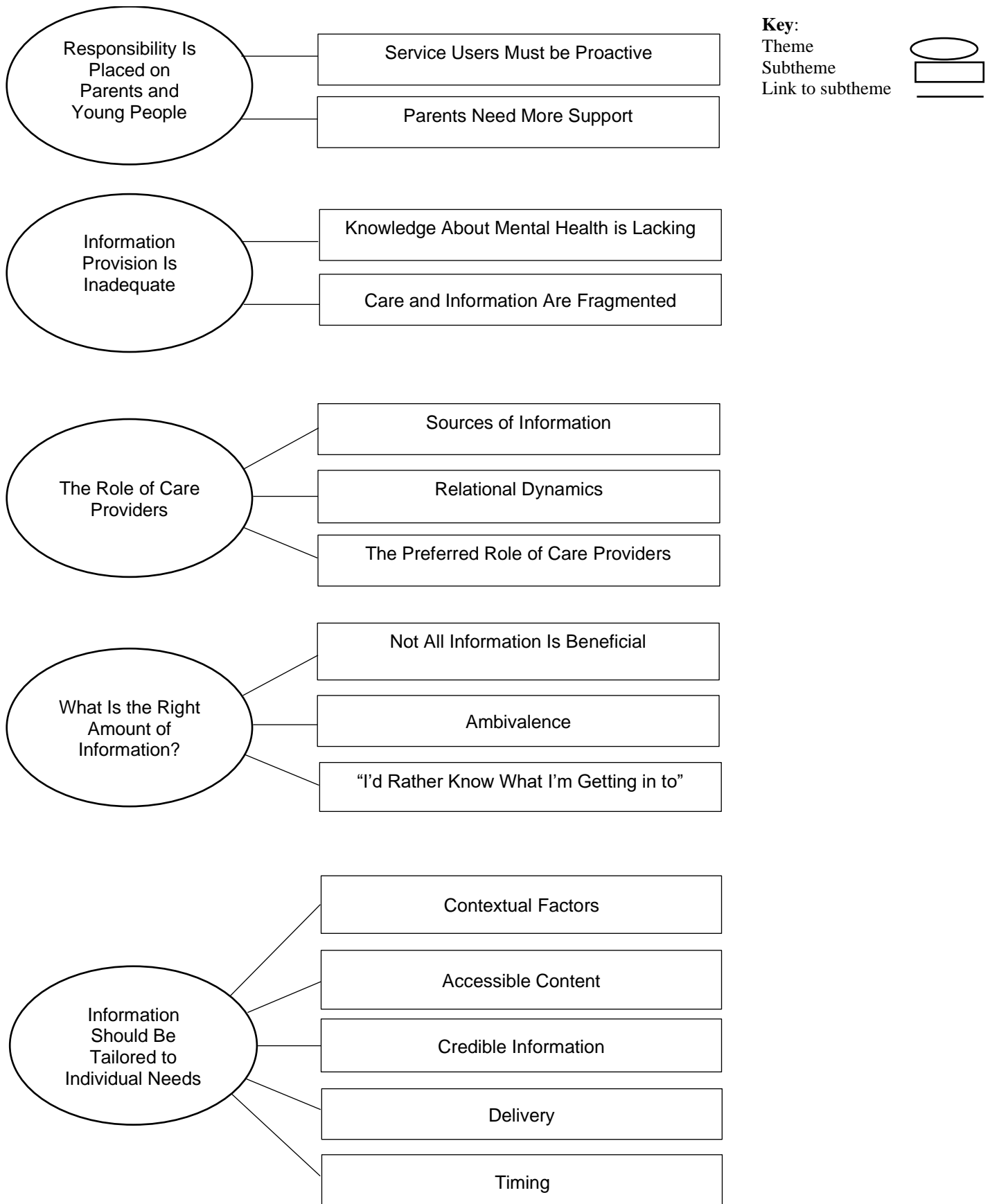
Results

This article reports five themes: ‘Responsibility is Placed on Parents and Young People’ describes how parents felt responsible for gathering information and wanted more support; ‘Information Provision Is Inadequate’ highlights the lack of knowledge about mental health and that information provision is fragmented; ‘The Role of Care Providers’ shows how information was provided, the impact that clinician-client relations had on information sharing and the preferred role of clinicians; ‘What Is The Right Amount of Information’ notes parents and young people’s preferences and ‘Information Should Be Tailored to Individual Needs’ highlights factors that must be considered when delivering information.

A thematic map (Figure 3) displays the themes and subthemes yielded from the data. Long extracts of data were shortened by using ‘.....’ for brevity. Natural pauses in speech were shown using ‘...’. Words added by the researcher were placed in brackets and italicised to give context or anonymise data. The themes will be discussed with examples from the transcripts.

Figure 3

Thematic Map Showing 5 Themes and 15 Subtheme



Theme 1: Responsibility Is Placed on Parents and Young People

Service Users Must be Proactive

Some YPWE and parents felt it was their responsibility to obtain mental health information, meaning they had to be proactive in unassisted information seeking.

(In relation to mental health in epilepsy) “So I think I ...I know a bit but that's because we've done quite a lot of research ourselves ... you know to find out about it ... and we have spoken to lots of different, you know doctors, neurologists” (P8)

Most parents said that they used the internet to find information. This was described as time-consuming and tiring. Some parents expressed a need to understand the systems around the child to effectively find information, as summarised by two parents:

“You really do have to get stuck in if you've got half an idea what you're doing, you're OK ... But if you've got no clue, you'll just get swallowed up in a system and there'll be no support at all” (P2)

“I only find out about these things on my own. So, you know when (*my husband*) says to me ‘oh the kids are at nursery go chill for a bit’ ...well I'm not I'm sitting there looking up, you know things on the internet or you know finding groups or emailing people or asking questions ... So it's all

down to me to do it and if I didn't do it, I don't think we'd have anything ... we wouldn't have any support at all" (P7)

Some parents reported a responsibility to advocate for their child, as others will not, which led to the parents having to adopt multiple roles, including having to information share with organisations such as schools and HCPs.

"I've got to be the boss of my child. I've almost got to be a helicopter parent ... here you're dealing with different sides of stuff (*epilepsy and mental health*) and I've got to be that spokesperson and I don't have that choice and it can become a bit overwhelming and a bit tiring" (P1)

YPWE also had to share information with mental health services.

"I had to tell (*the counsellor*) because he hadn't yet done a course on epilepsy" (YP2)

One mother described her experience having to educate services around their child about epilepsy:

P4: "I'd educate them on what epilepsy was too"

Interviewer: "how did you find that process?"

P4: "Exhausting. It was just another person I had to explain that had never come across it. That's just another role for me to play, but I wanted to play it 'cause I wanted to advocate for my child"

Parents Need More Support

Many expressed they were not pleased with this obligatory responsibility and wanted additional support to obtain mental health information, especially from care providers. Additionally, parents often wanted services to support them in educating other systems, such as schools. Some parent's suggested a physical toolkit of information as this could be shared and used to educate others. Many parents wanted information to be more forthcoming and for HCP's to proactively ask about mental health, with structured guidance.

“that would be good ... they (*HCPs*) could like point you in the right direction ... they don't have to handhold you but just give you a little help. You know you could try this ...you contact them ... that wouldn't take me hours of doing stuff myself” (P7)

“Just more guidance, more support, and so perhaps after diagnosis amongst your leaflets, they can say right this is the telephone number to sign up for something you know, or you can come back and there's appointments for you as a parent, and there's also appointments for the child for support and you know mental health support plus information” (P2)

“it would be good if (*HCPs*) lead it (*the clinical interview*) and they ask questions you know based on their expertise ... drawing out points that you might not have thought about. Uhm, because you often have that

lightbulb moment when someone says, ‘can your child do this?’ and you go actually, no they can't and oh, I hadn't thought about it like that” (P5)

Theme 2: Information Provision is Inadequate

Knowledge About Mental Health is Lacking

The information that parents and YPWE received was deemed non-existent or inadequate by many, resulting in poor knowledge about mental health in epilepsy and the support available. For example, many felt unsure about the impact of epilepsy on cognition and behaviour. Some parents and YPWE said that their knowledge of the link between mental health and epilepsy came from personal experience.

(When asked if anyone had discussed mental health with them previously) “Oh no, I wasn't aware of it until I started noticing it inside myself” (YP1)

“I just wish I knew, uhm, how the uh epilepsy impacted mental health and vice versa 'cause I I don't really know enough about the two areas to be honest with you” (P3)

One young person explained they had a lack of knowledge about mental health, however felt content with what they had received. Other YPWE and parents described how lack of information, and thus lack of knowledge, had negative consequences such as increased anxiety and perpetuating misconceptions. Some could not remember whether they had been told about mental health in epilepsy.

Additionally, many parents felt that the mental health support their child had received was inadequate.

Care and Information Are Fragmented

A recurrent reason for parents and YPWE experiencing inadequate information provision was the belief that mental health services were poorly integrated into epilepsy services, which resulted in information and support provision being fragmented or siloed. Mental and physical health were deemed as separate entities with some parents noting that physical health was prioritised over mental health by HCPs.

“We don't have a holistic approach in this country ... like health is health and mental and physical and physiological... They're all the same thing, fundamentally. Um, it's totally Siloed” (P5)

(In relation to lack of mental health information) “Maybe the doctors don't see that link as important as we do perhaps... Perhaps they concentrate on treating the seizures and treating, you know getting the medication right and things like that and that *(mental health information)* is maybe something that comes a bit later, so when things settle” (P8)

Many reported poor communications between the systems around YPWE (such as schools, mental health services and physical health services). This resulted in

parents having to act as the communication link between services. Many expressed significant difficulties in accessing mental health services and were often faced with long-wait lists or referral rejections.

(Regarding Children and Adolescent Mental Health Services, CAMHS) “... after a five year fight I've only just had my first appointment because my daughter's mental health was decreasing and she started like hitting her head on the wall” (P3)

When young people did receive mental health support, this was often entirely separate from their epilepsy care which again led to a lack of communication and fragmentation of care.

(In refence to the communication between mental and physical health services) “It’s entirely separate..... The epilepsy service would ask us how we're getting on, but it didn't seem there was any kind of communication between the two” (P8)

Many parents said that they wanted a holistic approach to be taken, preferring an integrated service rather than fragmented care provision. Additionally, many expressed they would prefer to access all information from one place, rather than having to navigate numerous sources.

“I see the information for epilepsy that’s shared with parents as being quite fragmented. When there’s too much information it’s really difficult to navigate

and sometimes you've got to have things that are clear and really succinct else it puts people off. So even if you had brief sections of information (*in a website*) that were expanded once you clicked on one of those sections I think that would be fine” (P1)

Theme 3: The Role of Care Providers

This theme highlighted the key role of care providers, including schools and HCPs, in sharing mental health information. Many commented on the importance of relational dynamics between services and service-users, as well as what HCPs could do to support the acquisition of mental health information.

Sources of Information

For parents of YPWE, communication was often filtered through an epilepsy nurse. However, not all had access to an epilepsy nurse and some did not engage with their allocated nurse. Other care providers that gave general information about epilepsy, and less frequently mental health, included charities, disability social workers and physicians. All of the young people in the study used their parents as an information source and had received generic information about mental health from their school.

Relational Dynamics

Relational dynamics between service-users and HCPs were seen as factors that could hinder or facilitate the sharing of information. Three parents expressed power imbalances between themselves and service providers, including schools, which resulted in parent's feeling as if their experience and expertise was dismissed by those that held 'authority'. A more equal power balance was desired. In addition to equal power-dynamics, parents and YPWE expressed the importance of having a trusting, good relationship with HCPs that are sharing mental health information. This was summarised by a parent who reflected on a positive experience with their HCP:

“It's that power dynamic. I think she doesn't set herself up as ... She's she's very, she just listened ... I think it was listening and that she was interested to talk and she's sympathetic” “it's almost like within teaching you know you're not coming in as the expert and imparting your knowledge to somebody else. It's an active two-way process...so you know you talk about active learners ...you know if you're engaged in the process, you get more from it I'm sure” (P5)

Parents wanted a non-judgemental space to share their experiences regarding mental health. Three parents said that having an impartial professional to talk to, rather than a family member, would be beneficial:

“I would think it's easier sometimes to speak to somebody who's not emotionally involved, so I think that would be half the benefit actually ... having somebody who's not emotionally involved to talk to” (P2)

The Preferred Role of Care Providers

As highlighted in a previous subtheme, parents wanted more support and wanted clinicians to take a more proactive role in providing this information. Participants said that HCPs, such as General Practitioners (GPs), should ask about mental health and should provide more information on mental health. Hearing information about mental health from a HCP would be more tolerable than simply reading the information from the internet. Most parents and young people highlighted the importance of considering mental health in YPWE, and some explicitly expressed their desire for HCPs to also consider the relationship between the two. Parents also wanted clinicians to acknowledge the secondary mental health impacts, especially on parents.

“I do think the GP should be more involved in this. I do think they're the sort of the missing link here. I think because it would be local, I think the GP would be a perfect place to kind of share that information and do maybe even you know yearly or whatever check-ups on the child to check on how things are going... 'cause they could refer to CAMHS and stuff as well... But we we've never had any sort of support from them” (P8)

(in relation to mental health information) “I think with *(people with)* epilepsy it should be more upfront ... the GP's personally offering you advice *(about)* mental health, because that that would help with your epilepsy as well and the mental health side of things” (YP1)

The credibility of the HCPs was also discussed, with parents wanting information from an “experienced” (P2) trained professional that knew about both epilepsy and mental health. The notion of credibility will be elaborated on later under the subtheme ‘Credible Information’. As one parent noted when considering who should offer support:

“Fundamentally, support from somebody who understands epilepsy and the particular type of epilepsy that your child has because they all work differently” (P5)

Theme 4: What is the right amount of information?

Three subthemes were established. Participants did not always fit into one subtheme in isolation. Rather, some participants’ views spanned across multiple subthemes. For example, they acknowledged that not all information is beneficial but also wanted sufficient information to support with preparedness.

Not All Information Is Beneficial

A recurrent belief for many parents was that negative information was harder to process for themselves and their children. This resulted in both parents and YPWE actively seeking for information that reassured them and avoiding information that would cause further distress. Some parents said that they were targeted in how they used the internet for information and were reluctant to participate in peer support groups or forums as they did not want to hear others negative experiences.

(Regarding searching on the internet) “some of it is very negative, isn't it? I mean it is. It's not a positive outcome you're gonna read ... so you kind of look to somewhere else to find a more positive one, you know ... but obviously that is the message” (P8)

“I don't want to read bad outcomes that's always been my approach. I didn't want to read how likely it was he was going to die or or permanently have a learning difficulty that may mean he could never achieve anything” (P5)

It was also highlighted that ‘too much’ information about mental health could be overwhelming, both pragmatically and emotionally, and parents did not want to be “bombarded” (P1) with information. Some parents filtered the information available to young people based on whether they believed it would be beneficial for their child to know/whether the child was able to process the information. This aimed to ‘protect’ children from information that may cause distress or hypervigilance. Resultantly, some felt that not all information should be shared with children and a collaborative approach could be taken in which parents are consulted about what should or should not be shared. As described by one mother and one young person:

“So I think there has to be discussions with the family of how the best way to move it forward ... because if we're going to introduce to (*my child*) that epilepsy can give you anxiety, (*he*) is quite likely to go ‘Oh goodness’”
“And so I think there's areas where you really need the professionals to say

stuff but I think you really need them not to say stuff too” “but maybe in a in a way that we could do it as a team approach that's best for (*my child*) whatever that is” (P4)

“(information) probably would be easier to go through my parents because like my parents they could probably make it into a much more smaller and kind of ... not nicer, but a softer, sort of, way of explaining things ” (YP2)

There was a belief shared by some that not all information about mental health is beneficial to know and it can cause further distress for both parents and young people. As one parent noted:

“I hate the idea that I'm intentionally uninformed about some aspects of treatment ... but I'm gradually begrudgingly admitting what probably almost everyone said to you, which is there are some things they don't want to know because it would cause further distress” (P6)

The perceived ‘usefulness’ of the information was also a determinant in whether parents wanted to receive it:

"It can sometimes be unhelpful to know information about mental health If you're not going to be able to get help, do you really want to know how bad it's going to be?" (P6)

In sum, this highlighted the inner conflict many parents experienced in relation to receiving information. Information sharing was considered a “balancing act” (P1) in which parents wanted to be well informed, and thus empowered, but also wanted to avoid the emotional threat of distressing information. Additionally, the benefits of that information were limited by factors outside of the parent’s control (for example, systemic pressures such as lack of funding for mental health services). This closely tied in with the next subtheme of ambivalence.

Ambivalence

Ambivalence was more explicitly noted by some parents. There was a change in narrative across some parents, sometimes within the interview, about *what* and *when* information should be shared. This demonstrated the internal conflict that some faced and ultimately the complexity of sharing and receiving information. In relation to early intervention for mental health and cognition, one parent initially expressed their disappointment with a ‘watchful waiting’ approach, but then later expressed her understanding as to why this is the case:

(After expressing that ‘watchful waiting’ was negative) “To be honest having answered that question and giving it some thought I can now understand why those epilepsy nurses say let’s wait and see ... I don’t think we should be too reactionary as well ... I think it’s important to take a step back ... now I can see why they say let’s wait and see ... especially on the cognitive side of stuff because you don’t want to be too reactionary and just step in ... you’ve got to see if it evolves and if it does manifest over a period of time ... but having

said that **pause** you know I don't think there's a clear cut or short answer to this" (P1)

Regarding *when* information about mental health should be shared, one parent noted:

"Initially I was thinking quite early on, but now I sat and thought you know, now we've been speaking I'm not sure if that would be the best time to do it. Uhm, but maybe if it was written then the parent could, you know, have it and keep it and refer back to it... I think early is still better, you know 'cause then parents are looking out for Uhm, you know their child's mental health maybe a bit more seriously than they would have **pause** I think yeah, if there's a follow up then initially it would probably be best" (P8)

"I'd Rather Know What I'm Getting in to"

Two parents and one YPWE believed that receiving all information about mental health would be beneficial in supporting preparedness. Additionally, some highlighted that although *all* information may not be beneficial, receiving more than the current provision could support planning.

"I would rather know the bad because then I can plan" (P3).

“I think it's very important to be given advice to cope with mental health and stop it impacting you earlier on so you don't have as many seizures and you're not affected as badly” (YP1)

Opinions on the ‘right amount of information’ varied according to context and beliefs, highlighting that information should be tailored to individual needs, as discussed in the following theme.

Theme 5: Information Should Be Tailored to Individual Need

Contextual Factors

It was widely acknowledged by parents that every child with epilepsy is different and thus an individualised approach is needed. For example, not all will need mental health support.

“I think we need to be careful of what the ... approach, and I think it's not ever going to be a one approach fits all from the epilepsy side” (P4)

(when asked whether they would need information on mental health) “I'm not sure it would be as helpful to me as some other people 'cause I'm quite happy right now” (YP3)

Contextual factors that impacted information needs included demographic factors, co-morbidities, epilepsy-related factors, the child’s ‘readiness’ to hear the

information, and cognitive level. This was summarised by one parent who highlighted the information needed is often dependent on numerous factors.

“What you need to know depends on where you are in the process of treatment so it's contextual, isn't it, what you need to know is contextual around where you are in the treatment process or what track you are on”“We're coming back to that word, sort of contextual, depending upon the severity of the likely mental health impact and of the type of epilepsy and the prognosis for that epilepsy, and the severity of it” (P6)

Accessible Content

Many reported a desire for more information regarding mental health in epilepsy, including the increased risk of mood difficulties. However, the specific content varied across participants. Areas of desired content included information about the impact on cognition and behaviour, the signs and symptoms of mental health issues, strategies to manage mood difficulties, and contact information for relevant services and support groups.

“I think just making it clear that there is a direct link (*between epilepsy and mental health*) and that this is a possibility for you to bear it in mind, 'cause obviously you're the advocate for your child, so your child isn't gonna realise they've got you know mental health problems ... that's your job to understand that and look out for it ... and maybe some, you know, guidance what to do, who to contact, you know who you can get support from ... are there any you

know good NHS websites 'cause there are a lot of websites out there and obviously you know you tend to stick to the NHS ones where possible, but some of them sometimes they can be limited, so is there are any other good you know medical websites that would be useful and maybe like local authorities” (P8)

Parents expressed the need for additional information and support regarding the impact of epilepsy on the family, including the mental health of parents and siblings. Information for parents regarding how to speak to their child about mental health was desired by both a parent and a young person.

“Sometimes parents can't come up with like the questions because ...Uhm, but maybe like if the doctors like asked the parents about it and then if the parents can't find any questions then they could like try and like make up some questions in a really simple and nice way because ... Like softer way than asking it straight up” (YP2)

The importance of *accessible* information content was highlighted by parents and young people. They noted the importance of the getting the ‘right’ wording for mental health information, to avoid it being overwhelming nor distressing. Additionally, jargon was identified as a barrier to information exchange and people wanted information in simple, succinct language (both online and face-to-face). As aforementioned, some found too much information overwhelming, thus having manageable amounts of information was important.

“as long as you phrase it correctly and say you know you may feel like this or this may happen to you, then again you may not, but if you're ever feeling this way this could be the reason for it ... and just keep an open dialogue, I think” (P2)

(in reference to HCPs) “To be honest. Uhm, half the time I I don't understand them because they use such like large words and so I can't like I don't understand them” “I think like. Uhm, trying to make it as simple and less like really overwhelming” (YP2)

(when asked what would be helpful) “If they're (HCPs) saying a lot of stuff at once, maybe summarising it at the end” (YP3)

Additionally, information should be tailored to the young person's age:

“Uhm, I think it probably is age dependent. Uhm, obviously for younger kids Uhm, perhaps less needs to be shared with them ...Keep it rather more simple. Uhm for adolescents then, I'm sure it could be more open and it should be more open, really for both the the kids and the parents” (P2).

Delivery

The preferred method of delivery also varied across parents and young people, again highlighting that an individualised approach would be beneficial. One parent felt “inundated with websites” but saw benefit in having written information, such as

leaflets, to refer back to. Many expressed the perceived benefits of written, visual information, such as leaflets and social stories.

“Giving you a leaflet or something would really help because you can't, you know always straight away do stuff you might say immediately ...everything else is going on, so yeah, that would be brilliant, because even if in reception they just had you know those racks with leaflets on 'cause I always looked at them” (P7)

One reason for this was because parents said that information can be hard to process face-to-face due to various distractors; therefore, written information acted as a reminder.

“Uh, I don't think face to face 'cause it's always good to have reference material, isn't it? Because face to face you forgot what I said about half an hour later” (P3)

An initial face-to-face appointment with HCPs to discuss mental health information followed by leaflet was also a common preference. Many thought it would be helpful to have space to ask questions and exchange information about mental health with a HCP; this should be something that is offered to all that feel they need it.

Credible Information

It was frequently noted that parents wanted information from credible sources; however, the definition of credible sources varied. For example, some parents believed that peer support groups were less helpful as every child is different. Others felt that information from parents of children with epilepsy was more reassuring and appreciated expertise through lived experience.

“The one person who was really helpful to be honest is not the epilepsy nurses, it's not the school ... it's the mum who's gone through this” (P1)

Similarly, some parents identified that platforms of information can contain both reliable and unreliable information and it is important to be mindful of this when searching for information.

“I've joined like groups as well, like on Facebook and Instagram. I follow or join groups with other kids that've got cerebral palsy or epilepsy or developmental delay or anything related to his condition I know there's there's a, there's a lot of information and then some of it you just be careful with, 'cause every child is different” (P7)

Whilst some young people felt that it would be useful to meet other YPWE, others did not see value.

Parents and young people acknowledged that not all information on the internet was reliable; nevertheless, it was a major source of information, although this was sometimes through a lack of alternative options. One parent noted that in the

absence of access to suitable mental health advice, they were reliant on asking non-mental health HCPs mental health related questions as there was no alternative. The advice that was offered varied in terms of perceived usefulness and the clinician's willingness to engage.

“So, in other words we'd often be quizzing our non mental health expert consultants about little mental health things because there was no other way other than Google” (P6)

The Importance of Timing

A common belief shared by many parents was that mental health information and support was reactive. As noted by one parent describing her experience of mental health services for her child:

“so everything was done post instead of pre so five years ago I wanted somebody to look at an assessment” (P3)

Many wanted a more proactive approach or believed that early information provision is important and can reduce stress.

“It could never be early enough, I think to to help them deal with it. In anything that's life changing for a child, they need some support and and be able to talk to someone about their feelings and just be able to sound things out or be given information” (P2)

Some parents believed that information about mental health should be shared *before* mood related difficulties arise, others felt it should be shared only if concerns regarding mood are raised. Others felt it should be shared both before and if issues arise. Parents frequently reported that they needed time to adjust to the epilepsy diagnosis and information, generally, was hard to process during this time. Therefore, some opined that mental health information should be shared after the parents have had time to process the epilepsy diagnosis. One option suggested was to offer parents a follow-up appointment after the initial diagnosis appointment to discuss mental health in epilepsy.

“you are so focused on the child ... you just want to get home (*from the hospital*) and just wanna make sure they're better...but maybe like I said 3, 4, 5 days later, I think that would be better 'cause then you've calmed down a bit and then you get like ‘actually, how are you coping with all this? How are you feeling?’ ” (P7)

“The epilepsy nurse probably would have been on the scene.....within the first period of time, not too long after and she would have explained things ...but you're so tired and you're not really taking it in and you kind of feel as if this is the first, you're the first person that it's ever happened to” (P4)

“maybe give them (*parents*) a while to absorb you know the actual diagnosis and deal with that side of it and then after that perhaps you know acknowledge

that that's gonna have an impact on them and it's OK to feel concerned and worried and that there's things that you can you know you can get help and support with” (P2)

Discussion

This study aimed to gain insight into the current mental health information needs and preferences of YPWE and their parents. It investigated the disparities between the current and desired provision of information, as well as the ways to minimise these disparities.

The study revealed that many parents felt that the responsibility to source mental health information fell on them, which some described as time-consuming and tiring. Parents had to advocate for their child to receive care. They expressed a desire for HCPs to support them with this process and for information to be more forthcoming.

Overall, the current provision of mental health information was deemed to be inadequate. This was an important finding as this had previously been reported in adults (Henning et al., 2019) but not for YPWE and their caregivers. Inadequate information led to a lack of knowledge about mood-related difficulties in epilepsy and feeling that more information should have been provided by professionals. Similar findings were found by Henning et al. (2019) in their study of people (mean age 41.8) with epilepsy, which reported a discrepancy between the mental health information that people with epilepsy *wanted* and what they *obtained*, indicating a lack of information sharing about this topic. Within the current study, of those whose children

received psychological interventions, many felt that the care was inadequate. It has been noted that receiving insufficient information about available treatment options can result in people accessing inappropriate or ineffective care (Kobau et al., 2019; Mahendran et al., 2017). As many of the sample lacked knowledge it is possible that this also hindered their ability to access appropriate care. Furthermore, parents expressed difficulty in accessing mental health support. It has been documented that epilepsy-specialists lack adequate knowledge about mental health in epilepsy and these specialists may be reluctant to refer their patients to non-epilepsy professionals, such as psychologists (England et al., 2012). This could leave patients without access to appropriate mental health support or in receipt of inappropriate therapy that does not meet the YPWE's needs, as expressed by parents in the current study.

Many felt that information provision and support was siloed. Fragmented care led to inefficiencies in information sharing and the separateness of services required parents to act as the communication link. Poor co-ordination between mental health and physical health services in epilepsy has been well documented (Couldridge et al., 2001; Kobau et al., 2019). Inadequate communication between services may explain why people with epilepsy often fail to access sufficient care for behaviour and mood-related difficulties (Kobau et al., 2019). Despite aiming to be patient centred, services can unintentionally disempower people with epilepsy. For example, when people are dissatisfied with care systems, cannot access care, or perceive there to be poor continuity of care, this can emphasise a disempowered status amongst service-users (Bennett et al., 2020). This further highlights the negative implications of fragmented care. Parents wanted more integrated support in which physical and mental health were holistically considered. Bridging the divide between epilepsy and behavioural

health to provide integrated care is pivotal (Kobau et al., 2019) and ‘comprehensive epilepsy care’ should have psychological interventions embedded into routine clinical care (Michaelis et al., 2018). This integration may reduce the treatment gap for mental health issues whilst also ensuring service-users feel empowered by the services they use.

Rather than having to search for information across multiple sources, many wished to receive all information from one place such as a person or website. Charities, such as The Epilepsy Society, have developed their websites to cover a range of areas; however, as highlighted in this study, this should not be considered as a replacement to face-to-face information sharing. Given that one of the key roles of an ESN is to provide information and education to empower YPWE and their caregivers (Higgins et al., 2019), they may be in a good position to provide this information.

Care providers played a crucial role in the sharing of information. As found in previous literature, parents were key providers of information for YPWE (Harden et al., 2021). Parents desired balanced power-dynamics between service users and clinicians and they wanted their experience to be acknowledged and valued through an equal-partnership with HCPs. Parents expressed the importance of good bedside manner, such as physicians using active listening skills, taking an empathetic stance, validating their clients, and taking concerns seriously. The significance of these core clinical skills has been emphasised in previous epilepsy literature, with positive patient-clinician interactions improving patient empowerment and facilitating the information sharing process (Bennett et al., 2020). Parents wanted clinicians to consider the mood-related implications of epilepsy on YPWE and their family,

offering an opportunity to discuss mental health if necessary. Giving service-users an opportunity to communicate their needs and desires in appointments can allow for an empowered patient-clinician relationship (Aujoulat et al., 2007; Bennett et al., 2020).

Regarding information needs, many felt that not all information about mental health, behaviour and cognition was beneficial to know and negative information could be hard to process. In response to this, some parents would actively avoid information or search for reassuring content. Reassurance seeking and/or avoiding 'negative' information is not an uncommon coping strategy to appease anxiety; however, it can lead to unintended consequences such as perpetuated anxiety which can be disruptive for YPWE and their families (Case et al., 2005; Stark & House, 2000). Additionally, YPWE and parents said that too much information could be overwhelming, both pragmatically and emotionally, and parents chose to filter the information they shared with their child. Parents acting as 'gatekeepers' of knowledge for their epileptic children has been documented (Harden et al., 2021). This highlights how important it is to ensure parents are appropriately educated considering they are a key source of information for their children. Parents and one young person explicitly wanted clinicians to take a collaborative approach, with parents being consulted about how and what information to share, to ensure that information being shared was appropriate for *their* child. This highlighted how important it is for clinicians to provide an appropriate level of information that is framed in a sensitive, non-threatening, digestible way whilst considering the needs of both the young person and caregivers. This may reduce anxiety and the reliance on potentially unhelpful information searching strategies.

The perceived usefulness, and relevance, of information determined whether parents wanted information. This closely tied in with the concept of self-efficacy – if knowing information about a topic does not allow people to alter the outcome (for instance, if there is no accessible treatment) then they are unlikely to see benefit in seeking information (Case et al., 2005). An inner conflict was noted in which some parents and young people did not want information withheld from them but they also wanted to avoid the emotional distress this information may cause. Parents tended not to express a polarised view of whether they wanted information or not, rather some highlighted the uncertainty about the finer nuances of *how* and *when* information should be shared. This showed the complexity of sharing sensitive information with clients and the delicate balance of providing enough information to empower people but also being mindful to not cause further distress. It is important to consider this ambivalence as it can influence information seeking or avoidance (Zhao & Cai, 2008).

Conversely, some wanted to know *all* information about mental health as this could help with preparedness. This was consistent with Lewis and Noyes (2013) who noted that YPWE believed that knowing information supported self-management of epilepsy.

In line with existing literature, parents and young people expressed the need for information to be tailored to individual need (Lewis et al., 2010). Contextual factors impacted information needs. For some, this was an unspecified need for information to be tailored, whilst others expressed the importance of considering the child's epilepsy-related experience, age, literacy level, and emotional readiness to hear the information. This was in keeping with existing epilepsy literature that

suggested age-of-onset, seizure type, co-morbidities, epilepsy severity, cognition, culture, and demographic factors all determined general epilepsy-related educational needs (England et al., 2012).

All parents reported that they wanted more comprehensive information about mental health in epilepsy. Specific content included information about mental health in epilepsy (for both YPWE and their families), signs and symptoms of poor mental health, coping strategies, ways to discuss mental health with children and contacts to support groups. This information should be tailored to individual-need to ensure it is accessible and fit for purpose. Consistent with previous literature, understandable, age-appropriate information from credible sources was desired (Nevin et al., 2020). This has been shown to result in improved education amongst YPWE (Lewis & Noyes, 2013). Although the delivery of information varied, many expressed a desire for both a face-to-face appointment, in which mental health is considered and discussed, and written information to refer to. Not only does person-centred, individualised care increase empowerment but tailored information can also support parents to develop skills that encourage their child to manage their condition more efficiently (Lewis & Noyes, 2013).

There was variation in *when* parents wanted mental health information. However, a common finding was that it took time to emotionally adjust to the epilepsy diagnosis. This is important to note as this adjustment period will influence information processing and parents' information needs. For example, an epilepsy diagnosis can be overwhelming for young people and their caregivers. In turn, this anxiety can inhibit information processing and make new information feel threatening

(Couldridge et al., 2001). Therefore, it is important for clinicians to consider whether providing mental health information shortly after epilepsy diagnosis is appropriate. Indeed, Nevin et al. (2020) found that parents' information needs shifted to focus on their child's wellbeing, including mental health, approximately one-year post diagnosis. Ongoing, regular, scheduled assessments to determine the information and support needs of YP and their parents in relation to mental health would be beneficial for parents in this study; this was recommended within the NICE guidelines (NICE, 2022).

Drawing on the CMIS (Johnson & Meischke, 1993; Ruppel, 2016) the current study found that health-related factors such as: beliefs related to efficacy (e.g., "If you're not going to be able to get help, do you really want to know how bad it's going to be?"); salience ("I'm not sure it would be as helpful to me as some other people 'cause I'm quite happy right now") and personal experience with information sources (feeling "inundated with websites") all influenced how participants perceived the relevance and credibility of information. In turn, this influenced what information they wanted, how they sought information and their preferences. This further supported the idea that information should be tailored to individual-need and as one participant noted, providing a "one-size-fits-all" approach would be inappropriate.

The mental health information needs of YPWE and their families is an emergent research area with relatively little understanding. The findings from this study shed light on the disparities between what YPWE and caregivers are currently receiving, which was largely inadequate, and what they would like.

Clinical Implications

The findings should be considered in the context of the NICE (2022) guidelines for the provision of epilepsy care for children, young people, and adults. Notably, the findings provided insight into potential factors for clinicians to consider when providing information on mental health. For example, the responsibility to obtain information should not fall entirely on parents, but instead should be provided by HCPs in an individualised, person-centred approach. Clinicians should be mindful of parent's and YPWE's existing knowledge, beliefs, experiences, and literacy-levels to ensure information is as appropriate as possible (Couldridge et al., 2001). At a wider service-level, the findings supported the notion that there should be better coordination between mental health and physical health services involved in epilepsy care. Effective multidisciplinary working relationships should support the communication between systems (NICE, 2022). Whilst not all parents had access to an epilepsy nurse, many felt it would be beneficial to have access to a 'central hub' of information. Again, this provided rationale for the implementation of the NICE guidelines that advocate for all people with epilepsy to have access to an epilepsy nurse that plays a "central role in providing information" (NICE, 2022., p.79). The importance of HCPs' effective interpersonal skills when sharing information was noted.

Overall, this study highlighted that the individual mental health information needs were not being consistently met. Person-centred, holistic approaches were not frequently utilised and information regarding mental health was scarce. This was

incongruous with the notion of patient-empowerment as described by the NHS (2018).

Strengths and Limitations

This is believed to be the first in-depth study to specifically investigate the information needs of YPWE and their caregivers in relation to mental health. This research allowed parents and young people to voice their experiences and preferences, giving insight into an unknown topic. A major strength was the methodological rigour and adherence to quality standards (Rapport et al., 2015). Qualitative research has often been criticised for biased results; although this limitation cannot be eliminated entirely, there are steps researchers can take to mitigate this risk (Mackieson et al., 2018). During data collection and analysis, the researcher used the principle of reflexivity to critically examine their own influence on the research process. The researcher reflected on their personal perspectives throughout the process within a reflective log and supervision; this allowed them to ‘bracket’ their assumptions and consider the impact of their beliefs on the analysis (Fischer, 2009). Credibility checks, such as respondent validation, ensured that data accurately reflected the participants views and resonated with their experience (Birt et al., 2016). Minor amendments were made to the report in-line with participants feedback on the respondent validation form. Embedding direct quotations enhanced the transparency of the data analysis process. The interview schedule was reviewed by a PPI group, this ensured that the questions were appropriate, relevant, and comprehensively covered a broad range of issues. To enhance understanding and manage the

subjectivity thematic analysis can bring, codes and themes were reviewed by a second researcher.

The dataset was analysed as a whole, rather than as separate participant groups (for example, separate themes for parents and YPWE). As parents and YPWE often present in clinics together, it was decided that both groups would be analysed together so that common themes could be identified across the dataset. This was also more time efficient. However, as there was a larger number of parents than young people it was possible that parent's views were overrepresented and not as representative of YPWE's opinions. This particularly troublesome as YPWE and their parent's views may differ. Research that utilises a larger number of YPWE could analyse the groups separately which would allow conclusions to be drawn regarding similarities and differences between YPWE and their caregivers; this may be warranted in future research.

Although generalisability is not the intention in qualitative research, the current sample consisted mostly of parents whose children had experienced mental, behavioural, or cognitive concerns. Additionally, all young participants had experienced difficulties with their emotion or behaviour. Beliefs and attitudes related to mental health are shaped by personal experience (Choudhry et al., 2016), therefore, information needs and preferences amongst these individuals are likely to differ from those that have not experienced (directly or indirectly) mental health concerns. Moreover, the self-selected sample may have had more favourable or unfavourable experiences of information exchange and differing preferences compared to those that chose not to participate, resulting in response bias. However, the varied responses

between participants suggests that this may not have been an issue. This was a predominantly white British, western-centric study and therefore findings are unlikely to be globally transferable as perceptions about mental health, epilepsy, and information preferences, vary across cultures (Moselhy, 2011). Furthermore, the sample of parents were predominantly women. A further limitation was that only three YPWE were recruited and all were a similar age. This is unsurprising as children with chronic-conditions are often considered a 'hard-to-reach' population (Clavering & McLaughlin, 2010); however, it is possible that the study aims could not be sufficiently answered with the small number of YPWE that participated. Information needs have shown to vary with age (Lewis et al., 2010), thus this study may only provide a narrow insight into information needs of YPWE. Despite these challenges, providing demographic information about the sample will support the reader to make their own judgement about the transferability of the data.

Future Research

Further research utilising a larger, diverse sample would be beneficial to get a broad understanding of the mental health information needs and preferences in YPWE and their families. A quantitative survey could be sent out to a larger cohort; this may result in a higher response rate and a more representative sample. The anonymity of a survey could also increase the response rate, especially amongst young people or more 'hard-to-reach', 'hidden' populations (Ellard-Gray et al., 2015). In turn, this would allow for more generalisable conclusions and would allow for the examination of whether the current themes are applicable to a wider population.

It would be beneficial to investigate the knowledge levels and information preferences regarding mental health amongst epilepsy clinicians. As highlighted in paper 1, there are gaps in knowledge regarding epilepsy amongst clinicians. This may also be the case for mental health. Nevin et al. (2020) highlighted the need for further studies to investigate the perceptions and information needs of clinicians working within epilepsy services (Nevin et al., 2020). Exploring this further may shed light on the clinician- and service-level barriers that impede the exchange of mental health information. In turn, this may provide ways in which we can intervene or implement change to result in more efficient, relevant information exchange regarding mental health.

Conclusions

This is the first study to specifically investigate the mental health information needs amongst YPWE and their caregivers. The in-depth interviews provided comprehensive insight into participants experiences as well as their needs and preferences; an area that was relatively unknown. Overall, it was found that there were substantial unmet mental health information needs amongst the sample. Generally, parents wanted information to be more forthcoming and to not be solely responsible for sourcing information. There were considerable variations in the content, timing, and delivery of preferred information regarding mental health. However, there were some common preferences about how information and support should be provided at a clinician-level and service-level. Therefore, the results of this study are consistent with the recommendations from the NICE (2022) guidelines that

advocate personalised information provision that meets the needs of the service-users,
thus improving both knowledge and empowerment.

Paper 3.

Integration, Impact and Dissemination

The following section will provide a critical evaluation and appraisal of thesis as a whole. My personal reflections on the process will also be considered. The potential impact of the findings and anticipated dissemination will be discussed.

Integration

Concordance, Discordance and Synergy of Paper 1 and Paper 2

Whilst paper 1 investigated knowledge levels, paper 2 investigated information needs. Although there is a subtle difference between the two, they are closely related, as level of knowledge will determine one's information needs (Shakeri et al., 2018). Therefore, broadly understanding the literature regarding existing epilepsy-related knowledge amongst Young People with Epilepsy (YPWE) helped to situate the empirical project.

A common theme across papers was that there were insufficiencies in knowledge amongst YPWE. The systematic review highlighted that knowledge gaps existed across various domains. Knowledge regarding mental health was not adequately explored. This reiterated the need for research into mental health and further clarified the rationale for the empirical study. The empirical project also highlighted gaps in mental health knowledge amongst YPWE. It also showed that knowledge gaps were apparent in parents. An important finding across both papers was the notion that individual, contextual factors can impact knowledge-levels and thus need for information. Therefore, information shared should be tailored to individual needs.

There were differences in the sample across the two papers. Notably, the systematic review looked at nurses whereas the empirical paper did not. Originally, I had hoped to investigate the mental health information needs of epilepsy clinicians, given the important role they play in disseminating information (Sample et al., 2006), and the lack of research into their information needs (Nevin et al., 2020). However, despite emailing various charities and advertising through clinician mailing-lists, there were significant recruitment difficulties. A possible reason for this was the lack of NHS ethics and limited opportunities to access clinicians. Therefore, the voices and perspectives of clinicians are still relatively unknown.

Unlike the empirical paper, the systematic review did not include parents. Nevin et al. (2020) had recently published a systematic review investigating the information needs of parents of children with early-onset epilepsy, therefore, it was not deemed necessary to include this population. On reflection, the papers in Nevin et al.'s (2020) review looked at *how* parents wanted information and information preferences rather than current knowledge levels. Therefore, this may have been beneficial to explore further. Unfortunately, this was not possible due to time constraints.

Most of the included studies in the systematic review were cross-sectional, closed-ended surveys. Although this provided important data, I felt that it lacked depth and did not allow participants to elaborate on their answers. This meant that the reasons behind the answers were unclear. For example, *why* were knowledge levels low? (Were people not told or did they not understand the information they were

told?). Qualitative methodology would have allowed for the exploration of such questions. Resultantly, it reiterated the importance of using qualitative analysis for the empirical study.

Initially, a quantitative approach was considered for the empirical paper. I had planned on developing a survey that could be used to collect the views of as many people as possible. However, after searching the literature it became apparent that the mental health information needs of YPWE and their caregivers were unknown and a novel area. After discussion in supervision, and feedback from the University Research Committee, it was decided that a qualitative approach would be more appropriate to explore the information needs in more depth. More specifically, I hoped it would be able to shed light on *what* information people want and *why* they want this (Busetto et al., 2020). Therefore, paper 1 helped to inform the methodology of paper 2.

On reflection, changing from a quantitative study to a qualitative study elicited some anxiety within me as I had more experience with quantitative research. I was uncertain about my ability to conduct qualitative analysis and initially felt concerned about the subjectivity of the process. However, it was an excellent learning process and I developed an appreciation for the rich data that qualitative analysis can provide. I enjoyed the freedom that qualitative data provided, when compared to quantitative data, and I felt more engaged with the process.

Reflections On Paper 1

I found the synthesis of the systematic review results especially challenging. This was likely due to my inexperience conducting systematic reviews, and the lack of clear guidance about how to conduct a narrative synthesis of mixed methods data (Campbell et al., 2019; Hong et al., 2017). The heterogenous ways that knowledge was measured presented additional challenges. I wanted to avoid a reductionist summary of the literature that narrowly or inaccurately interpreted the data, but I also did not want to provide an unstructured, unsystematic representation (for instance, reporting every single item in a list). Instead, I wanted a clear narrative that comprehensively represented the data. Discussion in supervision helped me to refine my themes and clarify the overall ‘story’ I was trying to tell (Popay et al., 2006). I also looked at non-epilepsy related systematic reviews to better understand how other mixed methods reviews with homogenous data present their results. Again, this supported my understanding of how to structure my synthesis.

Generally, I found the quality appraisal difficult. This was partly due to the fact I found the Mixed Methods Appraisal Tool (MMAT) difficult to use. After scoping the literature and looking at Cochrane guidance, I could not find advice about the best quality appraisal tool to use for survey data. I decided to use the MMAT as I was already using it for my mixed-methods studies and noticed that they had a set of quality criteria for the appraisal of ‘quantitative descriptive data’, such as surveys. It had also been utilised in published systematic reviews. Although there were prompts to support the researcher to make decisions, I found myself feeling confused about my

judgements and concerned that they were subjective. To mitigate the risk of subjective bias, I ensured that my decisions were documented and consistent across studies. I used a second reviewer to independently rate the quality of a study against the MMAT criteria and utilised supervision to discuss my decisions.

Reflections On Paper 2

Interest In the Topic Area

The current project captured my attention as it closely matched with my interest of supporting individuals with epilepsy, including their emotional wellbeing. Prior to doctoral training, I worked as an assistant psychologist in a Neuropsychological service in which I conducted cognitive assessments for people with a diagnosis of epilepsy. Whilst working there, I was struck by the number of people that presented with psychological concerns. For me, it highlighted the need for more accessible mental health support. Therefore, a research topic that related to mental health in epilepsy felt particularly pertinent.

Recruitment

Recruitment was unexpectedly slow, particularly with YPWE. I explored various avenues of advertising. For example, I frequently advertised on social media, contacted charities, met with international epilepsy speakers, attended epilepsy youth groups, and met with epilepsy clinicians. Despite this, only 14 people registered their interest. Interestingly, all the people that I spoke with expressed the need for research

into mental health. Reflecting on this, it was wondered whether people were reluctant to participate due to perceived lack of benefit (Mfutso-Bengo et al., 2008). A common theme expressed was the wider systemic issues regarding the structure of healthcare in the UK. For instance, services being underfunded and fragmented, which were issues that were unlikely to change because of the research. As discussed previously, YPWE are a ‘hard-to-reach’ population and attempts to improve recruitment (for example, contacting schools) were futile. In hindsight, providing an individual monetary incentive rather than a prize draw may have encouraged more young people to participate. Only three YPWE participated and all were of a similar age. Additionally, the sample was not ethnically diverse. Therefore, the perspectives of children older or younger than 12-13 years of age, and from other ethnicities, are still unknown. This research should be considered the ‘first step’ to improve understanding.

Due to difficulties with recruitment, it was not possible to run focus groups, as initially planned. Instead, individual interviews were utilised. It was more difficult to address the power differential within individual interviews; however, it was made clear at the beginning of the interview that people did not have to answer any questions they did not want to. As the interview schedule did not change in content, it was hoped that it would still capture people’s experiences and perspectives.

Service-User Involvement

Service-user involvement was integral to the development of the project and has a beneficial impact on health-research (Crocker et al., 2017). Given the focus on empowerment in my research, I wanted to ensure Public and Patient Involvement

(PPI) was meaningful rather than tokenistic. I sought feedback on the recruitment poster, interview schedule and information sheet from a parental PPI group. Through their feedback, language was altered on the advertisement to improve comprehension and the interview schedule was changed. For example, one parent highlighted that young people and parents may not understand what is meant by mental health; resultantly, this was clarified at the beginning of the interview for both adults and YPWE. I was also made aware of potential power imbalances between children and their parents; I had not previously thought of this. As a result, young people were given the option to participate with or without their parent/caregiver.

Interview Process

Many participants conveyed emotive stories about their experiences of mental health in epilepsy. Although not always directly related to the research questions, I was grateful that people felt comfortable to share their experiences as it highlighted the importance of conducting research into this unknown area. Participants' openness may have also reflected the safe interview-space I tried to create. I also wondered whether the lack of space to discuss mental health, due to reasons discussed in paper 2, meant that this was the first opportunity parents had to share these events. Therefore, the interview may have provided a space for parents to 'offload'. This further highlighted the need for such therapeutic spaces to exist and the potential isolation parents may feel. As noted by one parent:

“...With the epilepsy, I don't think I've spoken to anybody..... No, that's probably why I'm ranting at you here, sorry”

I reflected on my position as both a Trainee Clinical Psychologist and researcher and found myself wanting to allow participants to elaborate on their narratives, whilst also being mindful that this was not a therapy session. I believe my dual role helped to create a containing space for participants.

When parents were sharing stories about their negative interactions with clinicians and their difficulties accessing mental health support, I found myself sharing parents' feelings of anger and hopelessness towards the current provision of mental healthcare. I used self-reflexivity to acknowledge these feelings during the interviews and then used my reflective journal and supervision to consider the impact these may have had on the interpretation and analysis of data.

Qualitative Analysis

Despite being a novice, I found the qualitative analysis for the empirical project more enjoyable than paper 1. This was likely due to Braun and Clarke's structured guidance. To prepare myself for conducting the thematic analysis, I watched various YouTube videos that gave step-by-step guidance and met with a PhD student that had utilised thematic analysis within her thesis. I also purchased Braun and Clarke's (2021) book and read a worked example of the thematic analysis process (Byrne, 2021). All of these steps helped to improve my confidence.

Although transcribing the data was laborious, it helped me to immerse myself in the data. I was mindful to avoid creating simple 'topic summaries' (a surface-level

list of responses) rather than themes which captured shared meaning unified by a central concept (Braun & Clarke, 2021). Although this was challenging, it meant that the results looked beyond semantic-level responses to highlight patterns of meaning across data, in accordance with Braun and Clarke's (2021) guidance. During the coding process I felt overwhelmed by the quantity of data and initially found it difficult to imagine how I would develop a clear narrative of themes across the entire dataset. However, through 'trusting the process' the patterns of meaning became clearer over time.

Braun and Clark (2021) emphasise the importance of finding a data management technique that suits one's own preference. I had transcribed and coded the data on NVivo. However, when I started developing the themes, I decided to print all my codes. Having the codes in front of me and physically moving them around in space, rather than on a computer screen, allowed me to engage with the data in a different way and supported me to make sense of the data in its entirety.

I found it challenging to change and discard provisional themes as it felt like wasted hours. However, ultimately, I had to consider the appropriateness of themes in relation to the research question and remind myself that changing or omitting themes was part of the 'refining' process that is pivotal to RTA.

Reflective Journal

I kept a journal of my thoughts and feelings throughout the research process. This helped me to reflect on my assumptions, preconceptions, and subjective experiences, as well as the impact these have on the research process. This supported methodological rigour and transparency through an audit trail of my decisions (Vicary et al., 2017).

Respondent Validation

Getting feedback from participants was important as it provided further reassurance that I had not let my personal biases inaccurately influence the interpretation of the data. It ensured an accurate reflection of participants' views, and allowed people to elaborate, clarify, or add any additional reflections (Kornbluh, 2015). An example of this came from one parent that provided feedback after the interview to clarify a point about not having someone to talk to about mental health. They clarified that it was not that they had no one to discuss mental health with per se, rather they did not have access to a psychologist which meant that they would be reliant on non-mental health professionals which were sometimes hesitant to discuss mental health as it was 'not their area'. Additionally, the advice offered was not always suitable. This felt particularly pertinent to the research question and seemed to fit well with the existing subtheme of credibility. Unfortunately, none of the young people provided feedback on the themes developed from their interviews. This increased the risk of the themes not reflecting the views of YPWE.

Impact

The findings from paper 1 and paper 2 have the potential to have an academic and real-life impact for people with epilepsy, their families, clinicians/researchers, services, commissioners, and policymakers.

Academic Impact

Paper 1 was the first systematic review to report the knowledge levels of YPWE and nurses globally. Paper 2 was the first study to comprehensively examine the mental health information needs of YPWE and their caregivers. Therefore, both have improved understanding and made a valuable contribution to the epilepsy-field of research. Paper 1 noted a lack of high-quality, cross-sectional research that explored knowledge. The benefits of future research using a single psychometrically sound, culturally sensitive measure of knowledge were also highlighted. Taken together, this provides suggestions for future research. Both papers reaffirm the need for further research into the understanding and preferences of mental health information for people with epilepsy, across the globe. The themes from paper 2 provide an awareness on a topic that was relatively unknown. However, research that further investigates this topic using larger, more demographically diverse samples is warranted.

Clinical Impact

Service Users

Paper 2 may help service-users to make sense of their experiences when trying to access mental health support/advice. It may be validating to know that people share similar experiences and lack of knowledge was often due to wider, structural issues outside of the persons control (such as lack of integrated care), rather than parents' inability to find the information. It may also help to manage expectations of people with epilepsy trying to access mental health support. This study has given a voice to service-users and their families regarding mental health, an issue that pertinent for this population.

Clinician Level

The findings from paper 1 highlighted gaps in nurses' knowledge. This could prompt clinicians to reflect on their own knowledge gaps and consider ways to reduce this gap (e.g., through attending training). Paper 2 gives professionals insight into service-users views that can improve clinical practice. For example, parents and YPWE expressed the need for clinicians (both mental health professionals and epilepsy clinicians) to consider the bi-directional relationship between epilepsy and mental health, as well as the importance of interpersonal skills when sharing information with service-users. Both papers highlighted factors that may impact knowledge levels, information needs and preferences amongst service-users. This understanding may support clinicians when making decisions about when/how mental health information is shared.

Parents communicated the negative implications of fragmented services on information sharing and mental health support. This provides justification for additional training for GP's, mental health professionals and epilepsy-clinicians that promotes the understanding of mental health in epilepsy, including the presentation and available treatment. This improved knowledge may support the integration of care across different professionals.

Charities

Parents expressed the need for a 'central hub' of information to improve accessibility of information regarding mental health. Therefore, the current findings could be utilised by charities to adapt their websites to make mental health information more accessible (e.g., having a designated section that can be identified clearly) in line with service-user suggestions.

Service Level

The charity 'Young Epilepsy' has created a petition to call on UK leaders to ensure that YPWE have mental health screening and support integrated into their care. This petition will be shared with NHS regional directors and NHS Northern Ireland, Scotland, and Wales Chief Executives. The findings from paper 2 endorse the notion that mental health support should be better integrated into epilepsy services to meet service-users' needs. Therefore, a lay summary of paper 2's findings could be shared

with the appropriate commissioners and policy makers to recommend that integrated care and information regarding mental health should be more readily available for YPWE and parents across the UK.

The findings from paper 2 could be disseminated to NICE committee members to elaborate on the NICE guidelines regarding care for people with epilepsy. The NICE guidelines (NICE, 2022) make many important recommendations regarding the provision of care for people with epilepsy, including the recommendation that mental health information should be shared. However, they do not suggest how or what information should be shared, specifically in relation to mental health in people with epilepsy. The findings elaborate on these guidelines by giving specific examples of factors to consider when sharing information. Personalised care is also advocated in the NICE guidelines (NICE, 2022). Many parents in the empirical study wanted mental health information shared with them, although in a personalised manner. Therefore, the current study provides further justification for such recommendations.

Access to integrated mental health information and support in epilepsy services is unlikely to occur without assistance from commissioners and organisational policies. Therefore, sharing a lay summary of the results with policymakers and commissioners may help to support the increased funding available for person-centred, integrated mental health support in epilepsy services. Ultimately, this would further benefit YPWE and their families. Approaching and disseminating the findings of paper 1 and 2 to beneficiaries will hopefully maximise impact.

Dissemination

The findings from the empirical paper have been presented to lecturers and students at Royal Holloway, University of London. Students and staff were provided with the opportunity to ask questions and it is hoped that this sparked interest in the research area. A lay summary of the research will be shared with participants and relevant charities (HOPE charity, Young Epilepsy, The Epilepsy Society, Epilepsy Action, Epilepsy Research UK). I have also been invited to present my findings on the epilepsy podcast 'Epilepsy Sparks', an educational series about epilepsy featuring clinicians, researchers, and other professionals.

A clinical lead within a paediatric epilepsy service registered their interest in accessing the results of the project. Therefore, it is likely that this research would be of interest to other clinicians in epilepsy services. I will seek to publicise the findings to healthcare professionals in paediatric epilepsy services around the UK. I will create a summary of the key recommendations for clinicians that suggest ways in which services can improve mental health information provision for those with epilepsy. This will support clinical practice and hopefully maximise the clinical impact. As noted previously, the research will be shared with key commissioners and policymakers.

Both papers will be prepared for publication to reach as wider audience as possible and increase the likelihood of impact. In order of preference, the empirical paper will be submitted to *Epilepsy & Behaviour* and *Seizure - European Journal of Epilepsy*. Order of preference was determined by the impact rating of the journals

(SCImago, n.d). These journals were selected as they both focus on psychological aspects of epilepsy, and they both accept qualitative or mixed-methods literature.

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Appendices

Appendix A

Quality Assessment Tools – Systematic Review

Table A.1.

The Mixed Methods Appraisal Tool Table of Scores.

<u>Author/Year</u>	<u>Screening</u>		<u>Study Design</u>															<u>Comments *</u>
	All Studies		Qualitative					Quantitative descriptive (cross-sectional descriptive)					Mixed-Methods (MM)					
	S.1	S.2	1.1	1.2	1.3	1.4	1.5	4.1	4.2	4.3	4.4	4.5	5.1	5.2	5.3	5.4	5.5	
Agarwal et al (2014)	Y	Y	-	-	-	-	-	0	0	0	1	1	-	-	-	-	-	4.1 non-probability 4.2 Target population: adolescence with epilepsy. Sample: adolescence with epilepsy from one institution (self-selecting). 4.3. A pre-established, validated questionnaire not used. Content validity established but reliability/piloting not done. Listed as limitation in paper. Measurements seem appropriate for research Qs 4.4 94.3% response rate. Doesn't comment on missing data (from table shows no missing data) or what would have been done with that data. 4.5 Statistical analysis seems appropriate.

Manski & Dennis (2014)	Y	Y	1	1	0	1	1	0	1	0	0	1	1	1	1	1	0	<p>1.1 Design appropriate for research Qs 1.2 Qual. data collection methods adequate and justified. 1.3 Although TA and GT appropriate, the authors allude to ‘modified GT’ which is not justified or explained. 1.4 Quotes included in themes and clearly linked to data. 1.5 Clear cohesion between sources, collection, analysis and interpretation. 4.1 Non-probability sampling. 4.2 Target population: female teenagers with epilepsy. Sample: female adolescence that were recruited online (self-selecting) 4.3 Variables are clearly defined and measured; however, unclear whether piloted or tested beforehand. 4.4. Cannot calculate. 4.5 Statistical analysis seems appropriate, seemed appropriate with conclusion ‘incomplete knowledge’. 5.1 MM justified 5.2 Good integration of Qual and Quant data. 5.3 Outputs adequately interpreted, merit in MM rather than two separate studies 5.4 No divergencies listed and/or clearly described 5.5 quantitative element weaker than qualitative</p>
Pauschek et al (2016)	Y	Y	-	-	-	-	-	0	0	0	1	1	-	-	-	-	-	<p>4.1 Non-probability 4.2. Target population: Children with epilepsy Sample: young people from one neuropediatric department (self-selecting). 4.3. Interview schedule based on Qs but not specified if validate/reliable. 4.4 89% response rate. Lost 2 pps due to difficulty understanding Qs but did not comment on the others. 4.5 analysis adequate and clear</p>
Ryu et al (2015)	Y	Y	-	-	-	-	-	0	1	0	0	1	-	-	-	-	-	<p>4.1 Non-probability sampling 4.2. Target population: Korean AWE and their mothers Sample: multicentre study involving 25 secondary or tertiary hospitals in Korea (self-selecting) 4.3. Use adapted measure of validated tool but not tested the psychometric properties of adapted questionnaire. Also used tool validated for population of much younger age. 4.4 Cannot calculate. 4.5 analysis adequate and clear</p>
Woltermann et al (2020)	Y	Y	-	-	-	-	-	0	0	0	0	1	-	-	-	-	-	<p>4.1. Non-probability sampling and no stratification done. 4.2 Target population: young people with epilepsy. Sample: young people from two university hospitals (self-selecting). Does not include ‘very young pts’ which</p>

																			they aim to generalise to. 4.3 Interview schedule developed by experts, informed by pre-existing questionnaire but psychometrics examined. 4.4 Cannot calculate 4.5 analysis adequate
Smith et al (2021)	Y	Y	-	-	-	-	-	0	0	0	1	1	-	-	-	-	-	-	4.1 non-probability sampling 4.2 Target population: adolescents and young adults with epilepsy. <i>Sample:</i> young people from <u>one</u> paediatric hospital (self-selecting). 4.3 Reliability of EKQ noted, however, modified version used and no indication of validity check. 4.4 7 additional families were approached but declined due to disinterest in research and/or feeling unable to handle the extra burden of completing paperwork at their visit. However, unclear whether they differed on specific variables. Primary outcome measure had no missing data. Authors list missing data in <10% on specific questionnaire and address this through list-wise deletion. Response rate 92.1% 4.5 statistical analysis justified
Toli et al (2013)	Y	Y	-	-	-	-	-	0	1	1	1	1	-	-	-	-	-	-	4.1 non-probability sampling 4.2 Target population: school nurses in Greek schools <i>Sample:</i> recruited from 226 primary and secondary special education schools and 94 secondary education vocational schools from all Greek prefectures (self-selecting). 4.3 Survey piloted to test for validity and reliability (results not listed), informed by literature review. 4.4 Response rate 85% for special education school nurses and 77% for VS nurses. 4.5 Statistical analysis justified.
Terada et al (2020)	Y	Y	1	1	0	1	1	0	1	0	1	1	1	0	0	1	1	1	1.1 qualitative design appropriate as develop theory to explain their research question 1.2 qualitative data collection method appeared appropriate for GT (open-ended survey Qs) 1.3 Although GT would be appropriate, the authors allude to 'modified GT' which is not justified or explained. 1.4 interpretation of results sufficient 1.5 coherence between sources, collection, analysis, and interpretation described. 4.1 non-probability sampling 4.2 Target population: nurse teachers in Japan. <i>Sample:</i> recruited from 900 nurse teachers. 602 responded from mainstream schools, 34 from Special educational needs schools, and four from

																			other schools (self-selecting). 4.3. Although survey developed by experts, no mention of piloting or testing of the psychometric properties. 4.4 71.1% response rate but did not investigate reason for non-responders not is it clear whether they met inc. criteria and decided to not participate or did not 4.5 statistical analysis appears appropriate to research Qs 5.1 Justification for MM design clear 5.2 Different components of study poorly integrated (e.g., unclear how both parts of the study were brought together to answer the research Qs), integration is not clearly listed throughout the study and does not appear to be brought together to form a complete picture. 5.3 the output data from the two designs is poorly integrated. Despite the authors reporting that the qualitative analysis can 'clarify' the answers on multiple-choice questions' this is not evident in their study. 5.4 no conflicts apparent between Qual and Quant output data 5.5. Qualitative section scores higher than quantitative.
Dayapoglu & Tan (2016)	Y	Y	-	-	-	-	-	0	1	1	1	1	-	-	-	-	-	-	4.1. non-probability sampling, No clear inc/exc criteria despite mentioning one later in paper. 4.2 Target population: nurses working at a university hospital located in eastern Turkey. <i>Sample:</i> nurses from internal medicine clinics at a university hospital. (self-selecting) 4.3 measurements appropriate and psychometrically sound- validity and reliability of survey reported in original document 4.4. 88.5% response rate. Reasons some decided not to complete questionnaire listed; however, impact on findings unclear 4.5 statistical analysis justified and clear.
Nishina & Yoshioka (2018)	Y	Y	-	-	-	-	-	0	1	0	0	1	-	-	-	-	-	-	4.1 non-probability sampling 4.2 Target population: nurses in the Sanin region of Japan. <i>Sample:</i> distributed to nurses across the Sanin region of Japan (self-selecting). 4.3 survey psychometrics not mentioned. 4.4. 52.2% response rate. 546 distributed 290 collected and 285 valid. Does not mention steps taken to address this. 4.5 5 statistical analysis justified and clear.

Harimanana et al. (2013)	Y	Y						1	1	0	1	1							4.1. probability sampling used. 4.2. Target population: health workers in the Lao PDR <i>Sample:</i> recruited from 11 province hospitals; 9 district hospitals; and 30 health facilities. All enrolled healthstaff participated (self-selecting). 4.3 Based on previous surveys, pre-tested on a pilot group for accuracy and comprehension. However, other psychometric properties not tested 4.4 All participants that were enrolled at the health facilities participated with no refusal or drop-out rate. Response rate 100% 4.5 Statistical analysis justified and clear.
Buddhiraja et al. (2020)	Y	Y						0	0	1	0	1							4.1 Non-probability sampling used 4.2 Target population: primary healthcare providers in a North-Western Indian district. <i>Sample:</i> Respondents were contacted through the District Chief Medical Officer. People working outside of urban limits excluded 4.3 piloted for test-retest reliability and internal consistency. Validity discussed 4.4. cannot calculate 4.5 Statistical analysis appears appropriate
Prabhu et al. (2021)	Y	Y	-	-	-	-	-	0	0	0	0	1	-	-	-	-	-	-	4.1 Non-probability sampling used, could have benefited from random sampling. Sampling procedure brief and unclear. Sample frame nurses from tertiary care teaching hospital in South India 4.2 Target population: nursing staff in India. <i>Sample:</i> Participant's recruited from one institution- tertiary care teaching hospital in South India 4.3 based on previous tools, content validity checked and piloted. However, reliability not mentioned. 4.4 Cannot calculate 4.5 Statistical analysis appropriate.
Hegazy et al. (2019)	Y	Y	-	-	-	-	-	0	1	0	0	1	-	-	-	-	-	-	4.1 non-probability sampling. 4.2 Target population: paediatric nurses at an in-patient paediatric department affiliated to Tanta university hospital (TUH), Egypt. <i>Sample:</i> 41 nurses from TUH inpatient department 4.3 Developed their own measure based on pre-existing measure based on Nishina & Yoshioka's but haven't reported the psychometrics in their study nor can they be traced. Translated language but tested validity of measure. Reliability tested. 4.4. Cannot calculate 4.5. statistical analysis clear and justified (descriptive)
Assadek et al (2020)	Y	Y	-	-	-	-	-	0	0	0	0	1	-	-	-	-	-	-	4.1 non-probability sampling 4.2 Target population: nurses in the city of Niamey, Niger. <i>Sample:</i> does not

																				state where or how they recruited (e.g., from multiple hospitals or one hospital?). However, generalisability listed as limitation as they only recruited public sector nurses 4.3 psychometric properties not listed, unclear how they developed questionnaire. 4.4. Cannot calculate 4.5. statistical analysis justified.
Abbas et al. (2019)	Y	Y	-	-	-	-	-	0	1	1	0	1	-	-	-	-	-	-	-	4.1 non-probability 4.2 <i>Target population:</i> nurses of hospitals affiliated to Babol University of medical sciences. <i>Sample:</i> 500 nurses working at educational hospitals of Babol (self-selecting). 4.3 Reliability and validity tested. Utilised by other papers. 4.4. Cannot calculate 4.5 statistical analysis appropriate.

Table A.2.

A table showing the quality criteria from the Mixed Methods Appraisal Tool (MMAT)

Study Design	Criteria
All study designs (screening questions)	S1. Are there clear research questions? S2. Do the collected data allow to address the research questions?
Qualitative	1.1. Is the qualitative approach appropriate to answer the research question? 1.2. Are the qualitative data collection methods adequate to address the research question? 1.3. Are the findings adequately derived from the data? 1.4. Is the interpretation of results sufficiently substantiated by data? 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question? 4.2. Is the sample representative of the target population? 4.3. Are the measurements appropriate? 4.4. Is the risk of nonresponse bias low? 4.5. Is the statistical analysis appropriate to answer the research question?
Mixed-Methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question? 5.2. Are the different components of the study effectively integrated to answer the research question? 5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? 5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? 5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?

Note. Adapted from “MIXED METHODS APPRAISAL TOOL (MMAT) VERSION 2018” by Q.N. Hong, P. Pluye, S.Fàbregues, S. Bartlett, F. Boardman, M. Cargo, P. Dagenais, M.P. Gagnon, F. Griffiths, B.Nicolau, A.O’Cathain, M.C. Rousseau, I. Vedel, 2018. Registration of Copyright (#1148552), Canadian Intellectual Property Office, Industry Canada.

Table A.3

Critical Appraisal Skills Programme (Qualitative Studies)

Included papers	Clear statement of research aims?	Qualitative method appropriate?	Research design appropriate?	Recruitment strategy appropriate?	Data collection appropriate?	Relationship between researcher and participant discussed?	Ethical issues considered?	Rigorous data analysis?	Clear statement of findings?	Is the research valuable?
Harden et al. (2021)	1	1	1	1	1	1	1	0	1	1
Lewis & Noyes (2013)	1	1	1	1	1	1	1	1	1	1

Appendix B.

A Template Advertisement Provided to Charities

----- OPPORTUNITY TO PARTICIPATE IN MENTAL HEALTH AND EPILEPSY
RELATED RESEARCH -----

Hello,

My name is Sasha, and I am a Trainee Clinical Psychologist at Royal Holloway, University of London. I am conducting research into mental health information needs in epilepsy. Currently, very little is known about people's preferences of receiving mental health information in epilepsy.

We are looking to recruit **young people with epilepsy, and their parents/caregivers** to share their experiences in an online interview. [Click here](#) to look the recruitment poster.

Everyone that takes part will be asked to join **one** online interview, to share their views and experiences. All participants will be entered into a **prize draw for one of two £50 vouchers**.

Please contact me (Sasha.barton.2019@live.rhul.ac.uk) to find out more information or to get involved in the research.

Kind regards,

Sasha Barton,
Trainee Clinical Psychologist

Appendix C.

Royal Holloway University of London Ethics Committee Approval

From: Ethics Application System <ethics@rhul.ac.uk>

Sent: 27 April 2021 19:49

To: Barton, Sasha (2019) <Sasha.Barton.2019@live.rhul.ac.uk>; >; Ethics <Ethics@rhul.ac.uk>

Subject: Result of your application to the Research Ethics Committee (application ID 2517)

PI: XXXX Project title: The perceptions of mental health information in relation to epilepsy - insight from parents, young people and clinicians

REC ProjectID: 2517

Your application has been approved by the Research Ethics Committee. Please report any subsequent changes that affect the ethics of the project to the University Research Ethics Committee ethics@rhul.ac.uk

Appendix D.

Recruitment Advertisement

**Are you the parent of a child with epilepsy?
OR
Are you a young person with epilepsy?**

Understanding Mental Health Information Needs in Epilepsy

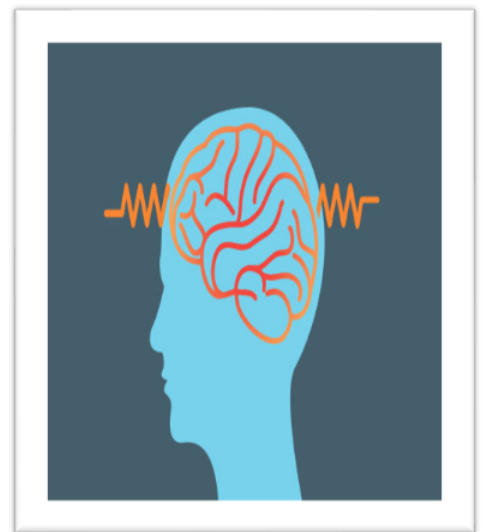
We are looking for **parents and caregivers of children with epilepsy**, or **young people with epilepsy (11-18 yrs)**, to take part in a study looking at the mental health support and advice available for those with epilepsy.

This will be a chance to tell your own stories and express your opinions.

What will it involve?

- Participants will be invited to join **one individual interview** to share their views and experiences.
- Those who participate, if they wish, can also take part in a focus group. This will be a chance to meet with other parents of children with epilepsy/young people with epilepsy.
- All participants will be entered into a **prize draw for a £50 voucher (2 available)**.

This research is being supervised by Prof. Roz Shafran and Dr Sophie Bennett, Great Ormond Street Hospital Institute of Child Health.



Want to know more?

If you would like to be part of this research, find out more, or have any questions, please email:

Sasha.barton.2019@live.rhul.ac.uk

Sasha Barton, Trainee Clinical Psychologist and Researcher

This project has been ethically approved by RHUL. Ethics Approval Reference: 2517



ROYAL
HOLLOWAY
UNIVERSITY
OF LONDON

 **UCL**

GREAT ORMOND STREET
INSTITUTE OF CHILD HEALTH

Appendix E.

Information Sheets.

E.1. Online Participant Information Sheet – Young People

Department of Psychology
Royal Holloway University of London
Egham, Surrey, TW20 0EX
www.royalholloway.ac.uk/psychology



Young People's Views on Getting Information about their Emotions and Behaviour

Please read the following information before you decide whether you want to take part in this study.

You can withdraw your data at any time, until we have completed the study. You do not have to give a reason. If you wish to do this, please contact one of the researchers on the information provided below

Who is doing this research?

- ◇ I am a trainee clinical psychologist at Royal Holloway University. I study emotions (e.g., sadness, happiness, worry) and behaviour.

What is the research about?

- ◇ We want to know what might help young people with epilepsy with their emotions and behaviour.
- ◇ We want to know **what type** of information about emotions and behaviour would be helpful for young people and their families, and **when** and **how** it should be given.
- ◇ We hope our findings will help hospital staff to talk to young people with epilepsy about their emotions and behaviour and share useful resources.
- ◇ We will also speak to parents and caregivers of children with epilepsy and hospital staff.



What will the study involve?

- ◇ If you agree to take part, you or your parent/caregiver will be sent an email with the date, time and link to an online interview.
- ◇ You will be asked to fill out a couple of questionnaires.
- ◇ During the interview, you will all be asked questions about getting information about your emotions and behaviour. This will be a chance to tell your own stories.



What happens with the things I say?

- ◇ Your answers are safe with us. Sound recordings of the interview will be deleted soon after they are finished.
- ◇ The only time we would tell someone about your answers is if we were worried about your safety or the safety of someone else.



Why should I take part?

- ◇ It will help us know what information would help children and young people with epilepsy, with their emotions and behaviours. This may make it easier for hospital staff to help other families and children/young people.

But...

This may take up some of your time. The questions shouldn't be upsetting but if you do feel upset at any time, you do not have to answer any questions you do not want to. We can also talk about how you can get help after the interview if you want it.

Do I have to take part?

- ◇ No, it is up to you.
- ◇ Even if you choose to take part but then change your mind, you can stop at any time. You do not have to give a reason.

How do I take part?

- ◇ If you would like to take part, please complete the consent form (attached to the end of this information sheet)
- ◇ We will then contact you and you will be asked to fill out questionnaires about yourself (e.g., your age, gender and type of epilepsy).

What if I have more questions?

- ◇ You can email me, on the email below, if you have any questions. You can also email my supervisors if you would prefer. This project is being supervised by Dr Sophie Bennett and Dr Anna Coughtrey.

Thank you!

Sasha Barton

Trainee Clinical Psychologist and Researcher
Email: Sasha.barton.2019@live.rhul.ac.uk

Dr Sophie Bennett

Email: sophie.bennett.10@ucl.ac.uk

E.2. Online Participant Information Sheet – Parents on Behalf of Children Under the Age Of 16

Department of Psychology
Royal Holloway University of London
Egham, Surrey, TW20 0EX
www.royalholloway.ac.uk/psychology



Dear Parent/Guardian,

Your child has the opportunity to participate in a research study that aims to investigate views on receiving mental health information in relation to their epilepsy. This is for every child with epilepsy, not just those experiencing stress or mental health concerns.

You can withdraw your data at any time, until we have completed the study. You do not have to give a reason. If you wish to do this, please contact one of the researchers on the information provided below.

My name is Sasha Barton. I am a postgraduate student of Clinical Psychology at Royal Holloway, University of London. For my final year research project, I am carrying out a study on mental health information needs in epilepsy. My project is supervised by Dr Sophie Bennett and Dr Anna Coughtrey. If you would like to discuss any aspect of the research with Dr Bennett or Dr Coughtrey, you can contact them by email on sophie.bennett.10@ucl.ac.uk, anna.coughtrey.10@alumni.ucl.ac.uk respectively. In the first instance, please contact me on Sasha.Barton.2019@live.rhul.ac.uk.

I hope the research will increase our knowledge of what and how much information patients and their families need in relation to mental health and how families want this information to be provided. In the future, this may help professionals to support other families and service-users to understand the links between mental health and epilepsy, which may include recommendations on how to access services.

All children who take part in this study will be asked to take part in an online interview. The interview will last approximately 60 minutes. A member of the research team will lead the interview and will ask questions about experiences of receiving mental health information and what information they think should be given to families in the future. These questions will simply be to guide the conversation. Children invited to take part in the study will be allowed to withdraw at any time if they do not wish to continue.

This study has been reviewed and approved by the College Ethics Committee at Royal Holloway, University of London. The members of the research team have been checked and cleared by the Criminal Records Bureau.

Please complete the consent form to indicate whether or not you agree to your child taking part in this study. Please retain this sheet for your future information.

Thank you for taking the time to read this information.

Sasha Barton

Trainee Clinical Psychologist and Researcher

Sasha.Barton.2019@live.rhul.ac.uk

E.3. Online Participant Information Sheet – Parents and Caregivers

Department of Psychology
Royal Holloway University of London
Egham, Surrey, TW20 0EX
www.royalholloway.ac.uk/psychology



Understanding Mental Health Information Needs in Epilepsy

You can withdraw your data at any time, until we have completed the study. You do not have to give a reason. If you wish to do this, please contact one of the researchers on the information provided below.

Invitation

You are being invited to take part in this research project. Before you decide whether to give your consent, it is important you understand why the research is being done and what it will involve.

Purpose and background to the research

There is a lack of research investigating the information needs of young people and their parents, with regard to the link between epilepsy and mental health. This study will look at what type of information caregivers and young people want and when the right time to give this information is. We will also look at how we can support clinicians to provide appropriate information about emotional and behavioural difficulties in children and young people with epilepsy.

This project will look at:

1. What information children and young people with epilepsy and their families/carers need and want, in relation to mental health and epilepsy.
2. How services can improve the provision of mental health information for those with epilepsy and their families, guided by feedback from service-users.

This research is being undertaken as part of the research requirements for a doctorate in clinical psychology at Royal Holloway, University of London.

Why have I been chosen?

You have been chosen because you are a caregiver or parent of a young person with epilepsy.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be able to keep a copy of this information sheet and we will ask you to complete a consent form. You can withdraw at any time, until we have completed the study. You do not have to give a reason.

What does the study involve?

- Participants will be invited to join one individual interview to share their views and experiences regarding mental health information needs in epilepsy.
- Those who participate, if they wish, can also take part in a focus group. This will be a chance to meet with other parents of children with epilepsy/young people with epilepsy.
- All participants will be entered into a prize draw for a £50 voucher (2 available).

What are the potential benefits of taking part?

Although taking part will not necessarily benefit you or your child immediately, it will increase our knowledge of what information service-users and their families want. In the future, this may help professionals to support other families and service-users to understand the links between mental health and epilepsy, which may include recommendations on how to access services.

What are the potential risks of taking part?

It is not predicted that the research will involve significant risks for you. However, the research will take up some of your time. We do not expect the interview to be too sensitive or distressing for you; however, you are free not to answer any of the questions. If you find anything distressing, we can talk about what support you may find helpful after the interview.

How will my information be kept confidential?

Your information will be stored securely. Your answers will be stored without your name on them. Pseudonyms will be given to everyone that participates so none of your responses can be linked to you. Audio recordings will be deleted as soon as the interview has been transcribed. Your consent form will be kept for 2 years, and your interview answers will be kept for 5 years, then destroyed. We will not use these for future studies. Additionally, signed consent forms will be kept securely and separately from transcripts.

Who is organising, funding and reviewing the research?

Royal Holloway, University of London, as part of the Doctorate in Clinical Psychology. The study has been approved by the Royal Holloway ethics committee (reference number: 2517)

How do I take part?

If you are interested in taking part in the study, please contact sasha.barton.2019@live.rhul.ac.uk. A member of the research team will then contact you to discuss your participation and you will be asked to complete a consent form and questionnaires. You will then be sent an invitation to an online interview.

What if I have more questions?

If you have any questions or concerns, please contact me, or my supervisors, on the emails provided below. This project is being supervised by Dr Sophie Bennett and Dr Anna Coughtrey.

Thank you for taking your time to read this information sheet.

Sasha Barton

Trainee Clinical Psychologist and Researcher

Email: Sasha.barton.2019@live.rhul.ac.uk

Dr Sophie Bennett

Email: sophie.bennett.10@ucl.ac.uk

Appendix F

Consent Forms

F.1. Consent Form – Parents/Caregivers

Department of Psychology
Royal Holloway University of London
Egham, Surrey, TW20 0EX
www.royalholloway.ac.uk/psychology



Please read this document carefully and ask any questions about anything you do not understand. Select the statements that you agree with.

- I confirm that I have read the information sheet for the above study, and I have had the opportunity to consider the information, ask questions and have had these answered.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
- I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.
- I understand that the focus group/interview will be recorded for transcribing purposes and shall be deleted as soon as this is completed.
- I understand that all data will be kept confidential, and that no personal identifying information will be disclosed in any reports on the project, or to any other party.
- If there are any concerns related to my safety, or my child's safety, then I agree for information to be shared with my GP/my child's GP.
- I agree to take part in the above study.

Print Name:

Signature:

Date:

F.2. Consent Form – Young People Over 16 Years-Of-Age

Department of Psychology
Royal Holloway University of London
Egham, Surrey, TW20 0EX
www.royalholloway.ac.uk/psychology



PLEASE CAREFULLY READ THE SENTENCES BELOW.

IF YOU AGREE, TICK THE BOX NEXT TO THE SENTENCE.

IF YOU DO NOT AGREE, LEAVE IT BLANK

You can ask a parent to help you.

If you are under the age of 16, you must get consent from a parent or legal guardian. They will be asked to also provide their name and signature.

- I have read the information sheet for study, and I have been able to think about the information, ask questions and have had these answered.
- I understand that taking part is optional and that I am allowed to leave at any time.
- I understand that the information collected about me may be used in other research but this will be anonymous (I can't be identified).
- I understand that the interview will be recorded but this recording will be deleted once it has been written up.
- If there are any worries about my safety, then I agree for information to be shared with my GP (doctor).
- I agree to take part in the above study.

Your Name:

Your Age:

Signature:

Date:

F.3. Consent Form and Assent Form – Parents on Behalf of Young People Under 16 Years-Of-Age

Department of Psychology
Royal Holloway University of London
Egham, Surrey, TW20 0EX
www.royalholloway.ac.uk/psychology



Please read this document carefully and ask any questions about anything you do not understand. Select the statements that you agree with.

- I have received an information sheet explaining the purpose of the study and have had the opportunity to ask further questions.
- I agree that my son or daughter may participate in the above research to be carried out.
- I agree that the interview can be recorded for transcribing purposes and they shall be deleted as soon as this is completed.
- I agree to my child's General Practitioner being informed if my child discloses any safety concerns.
- I am assured that my son's or daughter's right to privacy and confidentiality will be respected at all times.
- I understand that I may withdraw my son or daughter from the study at any point during the schedule of research. If my son or daughter indicates that he or she is unwilling to cooperate in the assessment session, their wishes will be respected.
- I consent to my son/daughter taking part in the research being conducted by Sasha Barton.

Signature of parent/guardian:

Name of parent/guardian:

Name of child:

Date:

Assent form for children under 16 years of age:

Please carefully read the sentences below. If you agree, put a tick in the box next to the sentence. If you do not agree, leave it blank.

- I understand what this research is about. (1)

I have been able to ask all the questions I want. (2)

I want to take part in this study. (3)

If any boxes are blank or you don't want to take part, don't sign your name! If you do want to take part, you can write your name below

Your Name:

Date:

Appendix G.

Parent Demographics Forms

Department of Psychology
Royal Holloway University of London
Egham, Surrey, TW20 0EX
www.royalholloway.ac.uk/psychology



About You

1. Gender Identity (please circle):
Male
Female
Other (please specify):
Prefer not to answer
2. How old are you (please circle):

<18
18-24
25-34
35-44
45-54
55-64
65+
Prefer not to answer
3. Ethnicity / Prefer not to answer
4. Were you born in the UK? Yes No Prefer not to answer

If no, where were you born?

If no, how old were you when you came to the UK?
5. Do you have any long-standing illness, disability or infirmity? [Long-standing means anything that has troubled you over a period of time or that is likely to affect you over a period of time]? (Please circle one): Yes No Prefer not to answer
6. What is your current employment status (please circle one below):
Employed full-time
Employed part-time
Unemployed
Self-employed
Retired (because of age)

- Retired (because of ill health)
- Student
- Other (please specify):
- Prefer not to answer

About your child with epilepsy

7. Child's Gender (please circle one):
 Male
 Female
 Other
 Prefer not to answer
8. Child's date of birth: / / Prefer not to answer
9. Please list your child's ethnicity: Prefer not to answer
10. Do you have any other children? (please circle)
 Yes No Prefer not to answer
 If yes:
 i. How many other children under 18 years are living at home?
 ii. Position of child in family (please circle one): Oldest Middle Youngest
 iii. Do any of the other children have any health problems? Yes No
11. Does your child attend school? (please circle)
 Yes No Prefer not to answer
 i. If yes, what year is your child currently completing?
12. Does your child have a diagnosed intellectual disability, developmental delay, any special needs or problems at school? (please circle)
 Yes No Prefer not to answer
 i. If yes, please describe:

13. What type of epilepsy does your child have?
 Prefer not to answer
 answer
14. How old was your child when they were diagnosed?
 Prefer not to answer
15. What professionals do you see regularly for your child's epilepsy? (please circle)
 Paediatrician
 Neurologist
 Epilepsy Nurse
 General Practitioner (GP)

Other (please specify):

16. How often has your child had an overnight stay in hospital due to their epilepsy? (please circle)

- Never
- Once
- 2-5 times
- 6-10 times
- 11-20 times
- More than 20 times
- Prefer not to answer

17. Does your child have any other medical / physical health problems?

Yes No Prefer not to answer

If yes, please list:

.....
.....

18. Has your child had, or currently have, any difficulties with their emotion or behaviour (please circle)? Yes No Prefer not to answer

If yes, please give more detail:

.....
.....

19. Has your child ever received support for emotional or behavioural difficulties? (please circle)

Yes No Prefer not to answer

If yes, please can you provide more detail:

.....
.....

20. Has your child ever received input from: (please circle)?

- A psychiatrist
- Clinical psychologist
- Family therapist
- Neuropsychologist
- Counsellor
- Other (please specify)

21. Does your child take any medication regularly? Yes No Prefer not to answer

i. If yes, please list them:

Appendix H.

Young People Demographics Form

Department of Psychology
Royal Holloway University of London
Egham, Surrey, TW20 0EX
www.royalholloway.ac.uk/psychology



1. How old are you?

2. I am a (please circle one):

Female

Male

Other (please specify):

Prefer not to say

3. What is your ethnicity?

22. Were you born in the UK? Yes No Prefer not to answer

If no, where were you born?

If no, how old were you when you came to the UK?

4. Do you know what type of epilepsy you have?

5. How old were you when you were diagnosed with epilepsy?

6. Do you take medication for your epilepsy? Yes No Prefer not to say

7. What professionals do you see regularly for your epilepsy? (please circle)

Paediatrician

Neurologist

Epilepsy Nurse

General Practitioner (GP)

Other (please specify):

8. How often have you had an overnight stay in a hospital due to your epilepsy? (please circle)

Never

Once

2-5 times

6-10 times

11-20 times
More than 20 times
Prefer not to answer

9. Does you have any other medical / physical health problems?

Yes No Prefer not to answer

If yes, please list:

.....

10. Have you ever had any difficulties with your emotion or behaviour (please circle)?

Yes No Prefer not to answer

If yes, please give more detail:

.....
.....

11. Has you ever received support for emotional or behavioural difficulties? (please circle)

Yes No Prefer not to answer

If yes, please can you provide more detail:

.....
.....

12. Have you ever seen (please circle)?

- A psychiatrist
- Clinical psychologist
- Family therapist
- Neuropsychologist
- Counsellor
- Other (please specify)

Appendix I.

Interview Schedule

[NB. Questions in bold, prompts underneath. QUESTIONS FOR FAMILIES IN BLACK, FOR YPWE IN BLUE]

Experiences (direct experience and vicarious experience, such as social networks)

What do you know about mental health in epilepsy? What do you know about mental health difficulties (low mood, anxiety) in people with epilepsy?

Prompts

Potential behavioural difficulties, learning difficulties and mental health (low mood, anxiety)

How important do you think the relationship between mental and physical health is in children in epilepsy? Do you think emotions and behaviour are important in children and young epilepsy with epilepsy?

Prompts

Why do you think that?

Do you think it is different for children with epilepsy compared to those without epilepsy?

What is your experience of receiving information about mental health for your child with epilepsy? What is your experience of receiving information about mental health?

Prompts

What content have they received in the past? (content)

What have you been told about the behavioural or mental-health problems that may be associated with epilepsy?

What were you told about the services available for young people with mental health difficulties and epilepsy?

How was this given to them? (format)

Formally (in medical settings)

Informally (e.g. support forums, other parents, TV...)

When was this given to them? (timing)

How useful was this information?

Where was this information given/Where did you receive this information?

Salience (applicability of information, health-threat and personal significance)

When do you think this information should be given? When would you like to get this information?

Prompts

Before or after MH difficulties arise?

Upon diagnosis?

What are your views on early intervention for mental health issues in epilepsy for your child? (*Question to tap into current threat views and personal significance*)

Do you think it would be useful for you and your child to receive information on mental health and epilepsy? Do you think it would be helpful to know more about mental health and epilepsy?

Prompts

Why?

Beliefs (risk perception and self-efficacy)

Have there been any barriers that have prevented you and your family from accessing information regarding mental health in epilepsy? Is there anything that's made it more difficult to get this information?

Prompts

If you weren't told, why do you think this information wasn't shared with you?

Have they searched for this information themselves (e.g., on the internet).

Information Carrier Characteristics (evaluation of the consumer)

Who do you think should share this information regarding mental health and epilepsy? Who do you want to give you this information?

Prompts

GP, Neurologist, Epilepsy nurse?

Why these people?

How would you like to receive this information? How would you like to receive this information?

Prompts

In what format (e.g., leaflets, forums, websites, face-to-face, a combination?)

Information Carrier Utilities (does the information meet the needs of the individual, is it important, purposive and topical?)

What information do you think should be shared with you and your child, in relation to mental health and epilepsy? What type of information about mental health and epilepsy would you like?

Prompts

What information do you think should have shared with you?

The links between MH and epilepsy

What services are available

Risk factors and 'warning signs'

What information did you wish you knew about regarding mental health and epilepsy?

Is there any information you wish you hadn't known/ information that was less helpful?

If you were designing a program to help parents caring for a child with epilepsy to inform them of the impact of mental health, what would help them the most?

Ending the Interview Schedule

'Is there anything I haven't asked you about in terms of mental health and epilepsy you think I should have in order to really understand the support that you would like?'

We've now come to the end of the interview. Thank you for taking the time to answer my questions. I have just a few more things to ask you:

- Would you like a summary of general findings at the end of the study?
- What would be the best way to send that to you?
- Are there any important questions that you think we missed out?
- Would you like to ask any questions or make any comments now that the interview is over?

Appendix J.

An Example of Coding from a Transcript.

Transcript	Codes
<p>I: Now, how would you like to receive information about mental health in epilepsy?</p> <p>P: I think like written would be best for me, so either a leaflet or a website.</p> <p>I think that's probably just personal choice though, 'cause sometimes I don't always take it in verbally ... so I like to go away and, you know, read it or think about it ... and then as well, if you've got it written, I always think you've got it then haven't you. You can use that to go back to it anytime share it with others as well.</p> <p>When do you think that information Should be given to you?</p> <p>Initially I was thinking quite early on, but now I sat and thought you know, now we've been speaking I'm not sure if that would be the best time to do it. Uhm, but maybe if it was written then the parent could, you know, have it and keep it and refer back to it... I think early is still better, you know 'cause then parents are looking out for Uhm, you know their child's mental health maybe a bit more seriously than they would have *pause* I think yeah, if there's a follow up then initially it would probably be best</p> <p>Do you have any kind of ideas why you might be a little bit more hesitant about hearing it early on?</p> <p>I think maybe there's quite a lot to take in ... so when you first read ... you know if a parent receives the diagnosis of epilepsy for their child it might be quite shocking. It might be quite a lot to come to terms with...UM, or maybe not ... maybe they'd suspected it ... you know, I guess it depends on the circumstance. For us it was quite shocking I guess 'cause it it all all these thing different things had happened. If it was a slightly different diagnosis, maybe not so ... Uhm, I was just thinking would it be sort of quite a lot to take in and understand in the initial appointment ... but maybe it maybe that's a good thing ... maybe that is something that does come hand in hand with epilepsy so needs to be kind of brought to their attention quite quickly.</p> <p>And who do you think should share that information with you?</p> <p>I I do think the GP should be more involved in this. I do think they're the sort of the missing link here. I think because because it would be local I</p>	<p>Written information useful to refer back to</p> <p>Individual preference for delivery</p> <p>Written information can be shared</p> <p>Ambivalent about when information should be shared.</p> <p>Written information useful to refer back to</p> <p>MH information should be shared before issues arise.</p> <p>Follow-up appointment should be offered.</p> <p>Parents' needed time to process epilepsy diagnosis</p> <p>Too much information early-on could be overwhelming</p> <p>Response varies according to individual circumstance.</p> <p>Ambivalence</p> <p>GP could provide MH information</p>

<p>think the GP would be a perfect place to kind of share that information and do maybe even you know yearly or whatever check-ups on the child to check on how things are going ... 'cause they could refer to to CAMHS and stuff as well ... but we we've never had any sort of support from them ... In a way, everything we had had came from the hospital ... but I I do think that the GP would be good 'cause 'cause the the hospital or the consultant although it is part of epilepsy and they probably could prescribe and treat it, maybe that would come under perhaps a different banner, wouldn't it ... it wouldn't come under mental health potentially ... I'm not sure 'cause we haven't had that conversation you know about treatment or anything ... but then you get maybe passed to another kind of consultant, perhaps so having it come from one place ... the GP would be good.</p>	<p>General information reduced after leaving hospital</p> <p>Parents want information from one place</p> <p>Parents want information from one place</p>
<p>Yeah, brilliant. So as you said coming from kind of one one place is quite useful.</p>	
<p>Yeah</p>	
<p>You said that you had CAMHS involved ... when you had CAMHS involved were quite well integrated in the epilepsy services or did it feel more separate?</p>	<p>Mental health services poorly integrated</p> <p>Poor communication between services</p>
<p>It was separate. Yeah ... it's entirely separate ... the epilepsy service would ask us how we're getting on, but it didn't seem there was any kind of communication between the two.</p>	
<p>What was that like?</p>	<p>Poor communication between services.</p>
<p>It's difficult, I guess. No, I guess no, it's not OK, but it's a big, you know. The NHS's such a big organisation that it probably is difficult for communication between you know the different services. I would say no, it didn't feel right.</p>	<p>Parents act as a communication link.</p> <p>Information provision inadequate</p>
<p>With CAMHS did you ever have to explain XXXX's diagnosis? How did the conversation come up?</p>	
<p>Yeah yeah, so we often have to do that ... but because we know doctor XXXX now you know he would sort of know us I guess to a certain extent he sees lots of children I'm sure but he always seemed to, you know, even if you read his notes or something, he always synced and sort of know and be on top of our his care and ... but yeah, at the CAMHS we did have to go through everything so it was a complete start from scratch and and that took probably about two sessions initially. It took quite a lot of time as I remember to go through everything.</p>	<p>Parents act as a communication link</p> <p>Poor communication between services.</p> <p>Parents act as communication link – time consuming.</p>

Appendix K.

Example of Respondent Validation Send to Participant 5

Dear XXXX,

You took part in a research interview about your views and perceptions of mental health information in epilepsy. Thank you very much for taking the time to talk to me about your experiences.

Below is a brief summary of the main themes of your interview. The main 'themes' are listed in bold. I would like to invite you to provide feedback on this summary, including its accuracy and the extent to which it captures the things that were important to you about mental health information in epilepsy. Please feel free to comment on any aspect of the summary, to point out anything I may have missed and to add any additional points that you have thought of since we spoke.

You do not have to provide any feedback if you do not want to.

If you would like to, please write your comments on the feedback sheet below and return it to the email provided.

Thank you very much again for kindly contributing to our research.

Yours sincerely,

Sasha Barton

1. Is there anything missing from the summary that you think is important?
2. Have you thought of anything else since the interview that you would like to add?
3. Any other comments?

Respondent Validation

Information Provision is Inadequate

This theme includes the current provision of mental health information, which overall appeared to be inadequate.

- Mental health and physical healthcare are often fragmented - clinicians can be more focused on stopping the seizures, sometimes at the expense of everything else. You said that mental health, including behavioural difficulties, were one of the main issues

as “that’s what (you’re) living with” and at times it has been “just as hard as the seizures”.

- When sharing information, you felt it was important to take a flexible approach and information should be “joined up” holistically, unlike the current system that is “siloes”. Integrated support from psychology could be beneficial.

The Role of Care Providers

This theme includes the preferred role of individuals and services that provide care, as mentioned by participants. For example, you mentioned:

- You felt that there was a power imbalance in which you felt “undermined”. A more balanced power-dynamic between yourself and clinicians was desired. Taking simple steps like introducing themselves, informing parents what their job is, and being trained in bedside manner could all be beneficial.
- The importance of a trusting relationship with healthcare professionals was pivotal.
- There was a desire for information to be more forthcoming and for healthcare professionals to proactively ask about mental health, with structured guidance.
- Mental health professionals should have a good understanding of epilepsy, as well as the emotional impact on the young person and the impact on the systems around the child (e.g., family).
- You said that the only person that has really shown interest in your child’s mental health is the local Paediatrician who was “empathetic”, “kind” and acknowledged the additional challenges of epilepsy beyond the seizures. You attributed this positive experience to the fact she listens and believes what you are saying. She has also been proactive with making referrals to services/charities that can support your family. Additionally, she gave you space and time to talk and at times offered reassurance (e.g., what you’re experiencing is normal for children with epilepsy). You also acknowledged that the power-dynamic between the both of you felt more balanced as she did not position herself as an expert that will impart knowledge on to you. Rather, it was more of a two-way, active process that was more engaging and you got “more from it” as a result.

What Is the Right Amount of Information?

This theme includes the type and amount of information that people wanted.

Negative information was harder to process

- If you were to Google information you may look at the impacts of taking medication. However, you would look for things that are reassuring and will “make (you) feel better”.
- You do not use Facebook groups as it can be “upsetting” to hear about other children with epilepsy and you would rather deal with any concerns with your child if/when they happen, rather than reading about other children’s current issues. You did not find these groups “reassuring” or “very supportive”.
- You said that you were careful about the information you accessed online. You did not want to read “bad outcomes” or know the worst-case scenario. You felt more comfortable accessing information on the Young Epilepsy website. You were wary of looking at medical journals as they can be difficult to understand.

Information Should Be Tailored to Individual Needs

This theme includes factors such as context, accessibility, credibility, timing and delivery of information, each of which should be tailored to individual need.

- You felt the psychological impact of epilepsy was just as bad as the physical. You thought it would be beneficial to have a psychologist embedded within the epilepsy team as you could access them if/when needed – this would be better than simply being told "your child is going to have terrible mental health problems". Ideally, the mental health professional should be someone who has insight and expertise in epilepsy.
- Ideally, there would be face-to-face appointments where the clinician leads the questions, as they may "draw out points that you might not have thought about".
- Personally, you would not want information about mental health to be shared with your child currently as you felt that they were "not ready to hear that (they have) any issues".

Appendix L

Reflective Journal Excerpts (Interview process and analysis)

- Interview with young person – could sense that the young person was somewhat nervous when starting the interview. They informed me that they had all the classes on Zoom during the pandemic. On reflection, I wonder whether they felt this interview mirrored some of the classes they had/ interactions with teachers. Again, this may have impacted power dynamics. Next interview with young person would be better to spend time building rapport and reassure no right or wrong answer (not a test!).
- Interview with parent today – a lot longer than other interviews. Parent got visibly upset when discussing their experience with their child. Asked whether they wanted to take a break but wanted to discuss their situation further and they said it's good to talk about it as "hadn't spoken about this". This made me reflect on my dual role as a researcher and clinician. Noticed myself wanting to use therapeutic techniques to support and validate, however, also mindful that this was a research interview and not a therapy session. Parents consistently reported a lack of space to share their experience and the psychological impact of the diagnosis.
- More generally, I'm starting to notice recurring theme of parents being ignored, feeling disempowered or having an unequal power imbalance with clinicians. I wonder what the process of sharing their experience was like with me, given they know my dual role. Perhaps this would impact what they're sharing. To discuss further in supervision.
- Starting to notice how a lot of parents use the space to 'offload' about their experience, wonder whether this was a reflection of the lack of space to do this? to have a safe space to discuss their concerns and worries regarding mental health?
- Red book on reflexive thematic analysis and coding. I think I was being too broad with my codes and they seemed more like themes. They mentioned that NVivo can make people jump a step or want to summarise their data more quickly through broader codes, I wonder whether this was happening for me? I'm going to re code the transcripts and re look through it, which seems like a daunting task but necessary. To discuss further in supervision.