



## RESEARCH ARTICLE

# Usual care for mental health problems in children with epilepsy: A cohort study [version 1; referees: 1 approved with reservations]

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**Background:** Epilepsy is one of the most common chronic paediatric conditions. Children and young people with epilepsy are at a significantly higher risk of developing mental health problems relative to the general population, yet the majority of these problems are unrecognised and under-treated in clinical practice. Although there is little epilepsy-specific guidance as to what interventions to use, researchers suggest there is no reason why clinicians should not be using the evidence base. Given the poor prognosis of untreated mental health difficulties, this cohort study sought to identify what psychological treatment young people with epilepsy with mental health needs receive in routine practice.

**Methods:** Participants were children and young people aged 3 to 18 attending paediatric neurology clinics. The parents of those children who met threshold for impairing symptoms on the Strengths and Difficulties questionnaire were asked to complete the Development and Well-being Assessment (DAWBA), an online clinical assessment designed to generate psychiatric diagnoses. Participants who met clinical threshold for a disorder according to the DAWBA were provided with a bespoke measure asking questions regarding their experience with treatment for mental health support.

**Results:** 16 of the 46 parents who completed the DAWBA reported that they had experienced previous or current support for their child's mental health difficulties. The mental health support offered to families was highly variable, inadequate and often not clearly compliant with existing UK National Institute for Health and Clinical Excellence (NICE) guidelines for mental health treatment in children and young people.

**Conclusions:** The present study demonstrates the inconsistency and inadequacy of mental health provision for children and young people with epilepsy. Future work should explore reasons for the treatments offered failing to adhere to existing guidance for mental health difficulties in children, as well as possible solutions to this.

**Keywords**

Epilepsy, Mental health, CAMHS, Paediatric


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report1 **Charlotte U. Rask** , Aarhus University  
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Any reports and responses or comments on the article can be found at the end of the article.

This article is included in the [UCL Child Health gateway](#).

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## Introduction

Epilepsy is one of the most common paediatric neurological conditions in childhood (Hirtz *et al.*, 2007). Children and young people with epilepsy have a greatly elevated risk of developing mental health difficulties relative to that of the general population (e.g. Rodenburg *et al.*, 2005) and of children with other Long Term Conditions, such as diabetes (e.g. Davies Heyman & Goodman *et al.*, 2003). Presence of psychiatric comorbidities may explain lower ratings in Health-related Quality of Life than seizure or demographic variables (Baca *et al.*, 2011; Stevanovic *et al.*, 2011). Further, poor mental health in children may contribute to a greater severity of physical illness (Miller *et al.*, 2009), for example the presence of a mental health disorder has been linked to a greater frequency of seizures (de Araujo Filho & Yacubian, 2013). As a result, the UK National Institute for Health and Clinical Excellence (NICE) guidelines recommend that the psychological needs of children with epilepsy should be considered as part of routine care (NICE, 2012, p.52).

Despite the recommendations from NICE, there is a lack of research into the optimal psychological treatment of mental health disorders in children with epilepsy (Jones, 2014), which means that there is little direction as to the types of assessments and interventions that should be used to identify and treat mental health difficulties in this group. The mental health difficulties most commonly seen in children with epilepsy are also those seen most commonly in children without epilepsy (for example anxiety, depression, disruptive behaviour, autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD); (Davies *et al.*, 2003) and there is a wealth of research supporting the use of evidence based treatments for these disorders in children without epilepsy (e.g. Weisz *et al.*, 2013). For example, UK NICE guidelines (2013) recommend that, in children and young people *without* epilepsy who have mental health needs, those with disruptive behaviour disorders should be given approximately ten hourly sessions of a behavioural parenting intervention as a first-line treatment and those with social anxiety should be given 8–12 sessions of cognitive behaviour therapy of 45 minutes duration (NICE, 2013). Given that cognitive behaviour therapy (CBT) and behavioural parenting interventions have been shown to work across a number of different populations, including those with Intellectual Disabilities (Totsika *et al.*, 2017), Autism (Lang *et al.*, 2010) and ADHD (Daley *et al.*, 2014), it is most parsimonious to assume that they also work in children with epilepsy, until proven otherwise. Therefore, in the absence of epilepsy-specific guidance, Wagner & Smith (2006) suggest that clinicians should use evidence-based interventions with routine outcome measurement (p. 47).

However, it is not clear that children with epilepsy are accessing these evidence-based treatments, and in many cases the difficulties remain 'under-recognised and under-treated in clinical settings' (Pattanayak & Sagar, 2012, p. 16). For example, Hanssen-Bauer & colleagues (2007) found 77% of 74 children and young people with epilepsy had a probable mental health disorder, but 80% of this group had no contact

with psychology or psychiatry, a finding corresponding to other studies (Ettinger *et al.*, 1998; Ott *et al.*, 2003). This finding of an unmet need is not new and indeed warrants further investigation. These studies also demonstrate that a small proportion of children and young people *do* receive support for their mental health needs but there is little research exploring what this treatment consists of and whether it is compliant with national recommendations for children with identified mental health needs. The primary aim of this study was therefore to identify what psychological treatment young people with epilepsy with mental health needs receive in routine practice. The secondary aim was to establish whether the treatment received was compliant with NICE recommendations for the mental health disorder.

## Methods

This cohort study formed part of a larger unpublished study investigating the feasibility of a randomised control trial for treatment of mental health difficulties in children and young people with epilepsy (NIHR Programme Development Grant RP-DG-0614-10003). It received ethical approval from the South East Coast – Surrey Research Ethics Committee (15.LO.1881) and R&D approval from Great Ormond Street Hospital for Children NHS Foundation Trust. We used the STROBE cross sectional checklist when writing our report (von Elm *et al.*, 2018).

## Procedure

Participants were parents of children and young people aged 3–18 years attending paediatric epilepsy clinics at any of the participating recruitment sites (North East London Foundation Trust; Great Ormond Street Hospital for Children NHS Foundation Trust; Whipps Cross University Hospital; University College London Hospitals NHS Foundation Trust and Whittington Health NHS Trust) between January 2016 and June 2016. The exclusion criteria for this study were minimal and restricted to those with profound intellectual disability.

Participants were asked to complete the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). Those who met threshold for significant emotional or behavioural symptoms were asked to complete the full Development and Well-being Assessment (DAWBA), an online clinical assessment designed to generate psychiatric diagnoses (Goodman *et al.*, 2000). Caseness on the SDQ was defined as the combination of raised symptom score ( $\geq 14$  out of a maximum of 40) and raised impact score ( $\geq 2$  out of a maximum of 10; Goodman *et al.*, 2002). Implicit consent was given for SDQ completion (as this is completed as part of routine practice) and full written informed consent was obtained for participants who scored above the threshold for impairing symptoms on the DAWBA.

Following DAWBA completion, parents completed a bespoke questionnaire measure containing questions which addressed their experience of accessing support for their child's mental health difficulties. This 'Experience of Support' questionnaire measure was designed specifically for this study by the research team with input from families of young people with epilepsy.

The questionnaire included open questions about what treatment they had been offered, the duration of support and when this was offered ([Supplementary File 1](#)). This questionnaire was completed electronically by participants. Participants were not offered any specific interventions or referrals for intervention.

Of the 121 participants who reached caseness on the SDQ, 46 parents completed the DAWBA (child age  $M = 116.15$  months,  $SD = 46.43$ ), 19 (41%) males; of these 29 (63%) met diagnostic criteria for at least one DSM5 disorder. The sample size is based on guidance regarding feasibility studies ([Julious, 2005](#)), therefore once 46 participants had completed the DAWBA we closed recruitment.

### Data analysis

Data was extracted and coded from the Experience of Support questionnaire by an independent clinically trained research assistant. Treatment was coded as useful if participants explicitly

stated that they had found the support they had received useful, or indicated benefit, in answer to question 5. Results were analysed using descriptive statistics.

### Results

Of the 46 participants who completed the DAWBA, 29 (63%) young people met diagnostic criteria for at least one DSM5 disorder. 19 of the 29 children meeting diagnostic criteria (66%) had not received previous support. 16 of the whole sample of 46 (35%) reported that they had experienced previous or current treatment for their child's difficulties. Of the 16 who did receive treatment, 10 (63%) considered it helpful in addressing their child's mental health needs. In total, 10 of these 16 children met diagnostic criteria for a mental health disorder according to the DAWBA (63%).

**Table 1** presents details of the treatment offered to families. Eight participants reported receiving support within the past year

**Table 1. Usual care for participants completing the Development and Well-being Assessment (DAWBA) and who had experienced support for the mental health difficulties identified.** GAD, general anxiety disorder; CAMHS, Child and Adolescent Mental Health Services; ODD, oppositional defiant disorder; ASD, autism spectrum disorder; ADHD, attention deficit hyperactivity disorder.

Participant	Diagnoses according to DAWBA	Support offered	Duration of support	Within past year?
1	Depression & GAD	CAMHS	Several months	N
2	Depression & ODD	CAMHS – psychiatrist, psychologist, counselling	>1 year	Y
3	Autism	Specialised health visitor offered practical advice and support	1/week for 2 months	Y
4	None	Family therapy through CAMHS	A few weeks	N
5	Autism	Behaviour management course for parents	6 weeks	N
6	ADHD & Separation Anxiety	CAMHS	A few sessions	Y
7	GAD and ASD	Dance therapy. Did not meet criteria for CAMHS.	6 sessions	N
8	ADHD	CAMHS and parenting classes at special school	One-off CAMHS appointment	N
9	Separation anxiety, ODD, ADHD	Outreach behaviour specialist	Continuous	Y
10	None	Social inclusion worker and school support worker	Unknown	Y
11	None	Art therapy and psychologist	6 sessions over 6 weeks	N
12	ODD and Separation Anxiety	CAMHS – advice on behavioural issues	1.5 years	Y
13	None	Psychologist	On-going	Y
14	ODD	Psychologist	1 month	N
15	None	Parent training	10 sessions over 10 weeks	N
16	None	CAMHS – individual and group sessions. Some mindfulness	6 months	Y

and all aspects of the treatment offered were highly variable. As can be seen from [Table 1](#), whilst some of the interventions may have been compliant with NICE interventions, many were not, for example a child that met diagnostic criteria for Generalised Anxiety Disorder and Autism (according to the DAWBA) received dance therapy.

## Discussion

This study revealed that the majority of young people with mental health needs in epilepsy services were not receiving any intervention. Of those that did receive an intervention, there was a great deal of variability in the mental health support being offered. The findings further strengthen the argument that a large gap in mental health provision exists within this group. Corroborating previous work, a large proportion of the participants with identified mental health needs were not in receipt of adequate support for these problems ([Children's Commissioner, 2016](#); [Ettinger \*et al.\*, 1998](#); [Hanssen-Bauer \*et al.\*, 2007](#); [Ott \*et al.\*, 2003](#)).

The lack of consistency and inadequacy of treatment for mental health difficulties demonstrated in this study may be owed to the failure to adopt an integrated, collaborative approach to mental and physical healthcare ([Naylor \*et al.\*, 2016](#)). Further, although evidence does exist for the treatment of mental health difficulties in children and young people, mental health clinicians may be reluctant to extrapolate this to children with epilepsy because of questions regarding their utility, efficacy and safety in this group. Some may hold the view that children with epilepsy need different approaches to those without epilepsy and the absence of treatments consistent with NICE guidelines demonstrated in this study may be reflective of such a belief.

To our current knowledge, this study is the first to formally investigate the routine treatment received for mental health problems within children and young people with epilepsy. However, in terms of the study's limitations, the sample size is small and limited in representativeness given the clinical sample. Additionally, it was conducted on the basis of parent report, which may be vulnerable to inaccuracies as parents may not correctly remember details of the support they received. Further, the lack of detail regarding the content of the treatment also limits our ability to definitively conclude how compliant the support was with current guidelines. Finally, we recognise that with the absence of a control group, the possibility that this problem may not be specific to children with epilepsy, cannot

be ruled out. Instead, this study may serve as another reflection of the problem with regards to Child and Adolescent Mental Health services (CAMHS) access and use of evidence based treatments that exist more generally ([Children's Commissioner, 2016](#)).

In conclusion, the usual treatment for mental health in children and young people attending paediatric epilepsy clinics is highly variable and inadequate. Providing appropriate, evidence-based treatment is a priority given the enduring impact that poor mental health has on children's quality of life. Further research should investigate reasons for the lack of treatment following existing guidance for mental health difficulties in children, as well as possible solutions to this. For example, qualitative studies of clinicians' beliefs about mental health treatment in epilepsy may be beneficial.

## Consent

Written informed consent for publication of research based on analysis of anonymised data were obtained from the participants.

## Data availability

NHS England has strict policies on data sharing with which the authors must be compliant. Participants did not provide explicit consent for their data to be publically available. Therefore data may not be made publically available due to ethical restrictions imposed by NHS England. The relevant anonymised data is summarised in [Table 1](#) and may be made available to qualified researchers. Data requests may be sent to the corresponding author of this paper or to [ich.psychmedresearch@ucl.ac.uk](mailto:ich.psychmedresearch@ucl.ac.uk).

## Grant information

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*The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.*

## Acknowledgements

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## Supplementary material

Supplementary File 1: Experience of Support questionnaire.

[Click here to access the data.](#)

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# Open Peer Review

Current Referee Status: ?

Version 1

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**Charlotte U. Rask** 

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This study explores the type of psychological treatment that young patients with mental health problems co-morbid to epilepsy receive in routine practice and whether this treatment is in accordance with NICE recommendations. Based on their results, the authors conclude that the treatment offered is inconsistent and inadequate, and that there is a clear need to optimise clinical practice in this area.

The topic of the paper is interesting and the introduction well-written with clear aims. However, there are some critical points related to the description of used methods and subsequently the interpretation of the results which the authors need to address and clarify:

1. The authors state that this study is part of a feasibility study prior to a planned larger randomised control trial for treatment of mental health difficulties in children and young people with epilepsy. However, no clear objectives or details of the design of this feasibility study are provided – the authors only state that they follow the STROBE cross sectional checklist when writing the report. Please provide more information.
2. The participants are recruited from four specialised epilepsy clinics. A bit more clinical information would be helpful, e.g. are the participants all new referrals or is it a mixture of children who have been followed for a long time in the clinics and children who are seen for the first time? This could be interesting in order to understand where the "gap" in the health care system is when it comes to identifying and initiating treatment for mental health problems in this patient group.
3. The main measure to identify mental disorders is the DAWBA. DAWBA is a broad diagnostic instrument that involves questionnaires, interviews and rating techniques, and it covers the most common child psychiatric disorders. Versions exist for various age groups (2-4 yrs, 5-17 yrs) and different informants (children from age 11 and parents) who independently of each other answer structured questions, which cover the operationalized diagnostic criteria for a broad spectrum of DSM and ICD diagnoses. Schoolteachers complete a shorter questionnaire. Open-ended questions record the respondent's own description of problems which makes it possible to perform a supplementary clinical rating in order to increase the diagnostic validity. However, in the current study it is not clear whether age corresponding versions were used. Furthermore, it reads as if no clinical rating of the interviews was performed, which might be a considerable limitation also as only one informant (i.e. one parent) was used to obtain information. Also, it could have strengthened the diagnostic findings if these were supported by information from other sources, e.g. medical records.

4. The authors state that 120 children reached caseness on the SDQ - but not out of how many? A flowchart would have been nice, also showing numbers for attrition in order to evaluate the generalisability of the study findings.
5. Criteria for caseness are based on SDQ scores. Please provide a bit more information on whether these criteria in general are used as standards to define potential cases with significant mental health problems within clinical study samples.
6. Please explain what is meant by the phrase: "threshold for impairing symptoms on the DAWBA". Do the authors here refer to whether or not there are positive computer generated diagnoses in the DAWBA interview?
7. The rationale for the chosen sample size is not clear for the purpose of this study. The authors only states that it is based on guidance regarding feasibility studies. N=46 actually seems a bit small to estimate the size of the clinical problem this study wants to elucidate.
8. Another main variable in the study, i.e. provided support for mental health problems, is assessed by a new measure which was not validated before its use. Furthermore, the rating is only performed by one person. This could introduce bias.

The mentioned methodological issues mean that the results should be interpreted with caution. They do suggest that there is a problem. However, it may be difficult to estimate the size of the problem based on this study.

In sum, the authors need to spend more time critically discussing their findings in relation to the weaknesses of their study design and used methods.

**Is the work clearly and accurately presented and does it cite the current literature?**

Yes

**Is the study design appropriate and is the work technically sound?**

Partly

**Are sufficient details of methods and analysis provided to allow replication by others?**

Partly

**If applicable, is the statistical analysis and its interpretation appropriate?**

Yes

**Are all the source data underlying the results available to ensure full reproducibility?**

Yes

**Are the conclusions drawn adequately supported by the results?**

Yes

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Child and Adolescent Psychiatry, functional disorders, pediatric liaison psychiatry

**I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.**

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