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Feasibility of telephone-delivered therapy for common mental health difficulties embedded in paediatric epilepsy clinics

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#### Abstract

# Background

Mental and physical health treatment should be delivered together for children and young people with epilepsy. Training health care professionals (HCPs) in epilepsy services to deliver mental health interventions is an important way to facilitate integrated care.

### Objective

To determine the feasibility of remotely delivered assessment and psychological treatment for mental health difficulties delivered by HCPs in paediatric epilepsy clinics with limited formal training in psychological interventions. We hypothesized that it would be i) feasible to train HCPs to deliver the psychological intervention and ii) that participants receiving the psychological therapy would report reductions in symptoms of mental health difficulties including anxiety, depression and behaviour difficulties and improve quality of life.

#### Methods

Thirty-four children and young people with epilepsy who had impairing symptoms of a common mental health difficulty (anxiety, depression, disruptive behaviour and/or trauma) were allocated to receive 6 months of a modular cognitive behavioural intervention delivered by a HCP with limited formal psychological therapy experience. Thirteen HCPs were trained in delivery of the intervention. HCP competence was assessed in a two-stage process. Parent-reported measures of mental health symptoms and quality of life were completed at baseline and following the intervention. Paired t-tests were used to analyse changes in symptoms over time.

#### Results

All thirteen HCPs who participated in the training were considered competent in therapeutic delivery by the end of the training period. Twenty-three patients completed pre- and post-

intervention measures and were included in the analysis. There were statistically significant improvements in: symptoms of mental health problems (p=0.01; Cohen's d = .62), total impact of mental health problems (p=0.03; Cohen's d = .52), anxiety and depression symptoms (p<0.01; Cohen's d = .57) and quality of life (p=0.01; Cohen's d = .57).

## Conclusion

A modular cognitive behavioural treatment delivered over the telephone by HCPs with limited experience of psychological therapy was feasible and effective in treating mental health problems in children and young people with epilepsy. Health related Quality of Life also improved over the duration of treatment. A randomised controlled trial is needed to demonstrate efficacy of the intervention.

#### 1. Introduction

Mental health disorders in children with epilepsy are common [1,2] and can impact severely upon quality of life [3]. Efficacious evidence-based psychological treatments are recommended internationally as first-line treatments for many mental health disorders in children [4]. However, there are significant problems with access to these interventions for children with epilepsy, and mental health disorders in this group remain both under-identified and undertreated [5,6].

There are multiple possible reasons for this under-identification, including diagnostic overshadowing by the physical health condition, lack of mental health provision for all children and young people locally, and stigma [7,8]. Epilepsy clinicians often lack training, knowledge and expertise in the management of mental health problems while mental health clinicians may feel unskilled in the treatment of children with epilepsy due to lack of knowledge about epilepsy or concerns regarding safety [8]. There is currently wide variability in the provision of psychology and psychiatry services in paediatric units in the UK, with some having no access to liaison services [9] and very few liaison services support long-term follow up and treatment [10]. In 2016, the children's commissioner reported that in the UK, approximately 5% of referrals to Child and Adolescent Mental Health Services (CAMHS) in 2015 were for 'emotional difficulties relating to physical conditions, including diabetes, asthma, neurological conditions and unexplained pain/somatising disorders [11]. However, the outcome of these is unknown for almost 80% of referrals and only around 11% received immediate provision [11].

There is increasing evidence that therapy can be delivered remotely and by people without extensive mental health training and this may be both cheaper and more convenient for families and services [12–14]. Children with epilepsy and their families want a therapist that

understands the daily challenges associated with medication, seizures and learning difficulties [15] and frequently turn to their epilepsy nurse to discuss concerns regarding emotional and behavioural difficulties [16]. Research in other areas has demonstrated that evidence-based therapies delivered by nurses working in physical settings can be both effective and highly acceptable to patients [17–19].

This paper reports on the second phase of a five-year research programme to develop and trial telephone-delivered therapy for common mental health difficulties integrated within paediatric epilepsy clinics and delivered by health care professionals (HCPs) in paediatric epilepsy clinics who do not have significant prior formal experience of psychological therapy. The first phase involved development of the intervention [20]. The second phase reported in this paper involved evaluating the feasibility of training HCPs to deliver the psychological intervention to the standards required for the randomised controlled trial (RCT) and examining the clinical outcomes for their patients. The intervention was delivered during the training phase by people with limited training in psychological therapy, including members of the epilepsy clinical team and assistant psychologists. The aim of this second phase was to determine:

- i) The feasibility of this method of delivering therapy for mental health difficulties in paediatric epilepsy clinics prior to progressing to the planned RCT (proportion of HCPs reaching competence in the training phase and proportion of patients completing six or more therapy sessions)
- ii) The within subject effect of the intervention on reported mental health and quality of life outcomes

### 2. Material and Method

### 2.1. Ethical approval

This study received ethical approval from South Central – Oxford A Research Ethics Committee (REC reference number: 18/SC/0250).

#### 2.2. Setting

Patients were recruited from secondary and tertiary paediatric epilepsy clinics in one specialist paediatric hospital and five general hospitals.

#### 2.3. Measures

All measures were parent-reported. Parent report was chosen as the primary outcome for data completeness, as self-report versions of the measures are unsuitable for younger children and those with significant intellectual disabilities.

## 2.3.1. Mental health - diagnostic

## 2.3.1.1 Development and well-being assessment (DAWBA)

The DAWBA [21] is a computerized clinical assessment that generates ICD-10/DSM-5 psychiatric diagnoses. It was rated for presence/absence of DSM5 mental health disorder/s by a trained clinical rater. Clinically rated DAWBAs demonstrate good external validity (k = 0.67 - 1.0) and inter-rater reliability (k = 0.64)[21]. The SDQ forms part of the DAWBA. The DAWBA was completed prior to being allocated to the intervention. The DAWBA assessment was based on parent report alone.

#### 2.3.2. Mental health symptoms and quality of life

Mental health symptom and quality of life measures were completed at baseline and six months after assessment.

## 2.3.2.1 Strengths and Difficulties Questionnaire (SDQ)

The Strengths and Difficulties Questionnaire (SDQ) [22] is a 25-item questionnaire used for the identification of common mental and behavioural symptoms in young people. It comprises five subscales (*emotions*, *conduct*, *hyperactivity*, *peer relationships* and *prosocial behaviour*), each with five items and scored 0-2. The total score (ranging from 0-40) is calculated by totalling all subscales except the *prosocial* subscale. For both the total scores and the subscale scores, lower scores suggest better mental health except the *prosocial* subscale where lower scores suggest lower prosocial skills. An impact supplement scale consisting of 5 items was also administered with scores ranging from 0-10. The SDQ is one of the most widely used measures of childhood psychopathology in the UK, and was chosen as the primary outcome measure since it is a general measure of psychopathology, so would be a meaningful outcome measure regardless of the initial type of problem for each participating child. It has good reliability (Cronbach's alpha = 0.64) and good concurrent validity (r=-.15 to .73, p<.001) [23].

#### 2.3.2.2 Revised Children's Anxiety and Depression Scale (RCADS)

The RCADS [24] is a 47-item questionnaire with robust psychometric properties, excellent reliability (Cronbach's alpha = 0.78) and good concurrent validity (r= .31 to .70, p<.01) [25] and is used to assess depression and anxiety in children and young people.

# 2.3.2.3 Paediatric Quality of Life Inventory (PedsQL) Generic Core Scales

The emotional functioning (five items) and physical functioning (eight items) subscales of the Paediatric Quality of Life Inventory (PedsQL) [26] examine health related quality of life. The PedsQL has excellent reliability (Cronbach's alpha = 0.90) and validity (r=-.50 to -13, p<.01) [27]. There are different versions of the PedsQL for different age ranges (young children aged 5–

7; children aged 8–12; teens aged 13–18). The appropriate questionnaire for the age of the child was used.

## 2.3.3. Personalised goals

## 2.3.3.1 Goal Based Outcome measures (GBOs)

All participants completed Goal-Based Outcome ratings [28] in which a patient sets their own goals for therapy and rates how much they think they have moved towards these goals on a scale of 1-10, where 10 is the goal has been completely met and 1 is no progress has been made.

GBOs were rated at each therapy session.

### 2.4.Participants and procedure

Clinicians within the epilepsy teams, including neurologists, paediatricians, and paediatric epilepsy nurses identified patients aged 3-18 who they considered would benefit from intervention for anxiety, low mood, trauma and/or behavioural difficulties and were attending clinics for the assessment and/or treatment of epilepsy. Exclusion criteria were: 1) ongoing psychological support, 2) primary mental health difficulty other than anxiety, depression or disruptive behaviour (e.g., eating disorder), and 3) risk to self or others requiring urgent assessment/treatment. There were no exclusion criteria related to intellectual ability or presence of neurodevelopmental disorders. Clinicians obtained parental permission to pass the child's details to the research team and the family were contacted by a research assistant who further explained the study over the telephone. Those interested were invited to complete a parent-report SDQ [22] either over the telephone or by email.

Parents of those children meeting a pre-specified threshold were provided with study information sheets and consent forms and invited to consent to the study. Children and young people provided assent when able to do so. Consenting parents then completed an in-depth diagnostic assessment, the Development and Wellbeing Assessment (DAWBA) [21] which was rated by a trained clinical rater to confirm presence of impairing symptoms of anxiety, low mood, trauma and/or disruptive behaviour suitable for the study treatment. Those confirmed to be suitable for the study treatment were invited to complete parent-reported baseline measures: RCADS [29] and PedsQL [26] and participate in the intervention. The intervention consisted of up to 22 sessions over 6 months and parents completed session-by-session measures including Goal Based Outcomes as part of therapy. The SDQ, RCADS and PedsQL were completed again at 6 months following completion of baseline measures. Families were contacted by a researcher who was not involved in delivering their intervention and asked to complete these 6-month follow-up measures.

#### 2.5.Intervention

The intervention was a modified version of the Modular Approach to Therapy for Children with Anxiety, Depression, Trauma, or Conduct Problems (MATCH-ADTC) [30]. This combines modules for the treatment of anxiety, depression and behaviour problems, taken from known evidence-based protocols, with an empirically derived algorithm for making decisions regarding which module should be used and when. It is particularly suitable for populations with significant comorbidity, as is often seen in young people with epilepsy and other neurological conditions [31], however it has not yet been evaluated in the UK or for young people with epilepsy. Key content of MATCH-ADTC for depression includes cognitive and problem-solving strategies and scheduling pleasurable activities; anxiety is addressed using exposure techniques;

behavioural strategies for disruptive behaviour and conduct disorders are delivered through the parents and include one-on-one time, praise, effective instruction-giving, rewards and ignoring unwanted behaviour; trauma is addressed through developing a trauma narrative, exposure and safety planning.

The MATCH-ADTC manual was modified for delivery within epilepsy services by non-mental health specialists [20]. It was personalised for the individual and context by (i) anglicising the language, (ii) using epilepsy-specific examples where possible (e.g. when discussing anxiety), (iii) making it explicit that the pace of the intervention and delivery may need to be adjusted on a case-by-case basis depending on the child's intellectual ability and mode of delivery (telephone vs. face-to-face) and (iv) allowing the anxiety intervention to be delivered via parents when appropriate and preferred. An epilepsy focus area was added to the manual as follows:

- 1. The addition of a core epilepsy practice module (i.e., required for everyone meeting epilepsy criteria) that provides education about mental health difficulties and their relationship with epilepsy, enables a formulation of the maintenance of mental health disorders within epilepsy, separates the child from the disorder and provides links to additional resources such as website links for charities with information about paediatric epilepsy.
- 2. Three additional optional epilepsy practice modules (i.e., available, but not required for everyone meeting epilepsy criteria) in keeping with the structure of MATCH-ADTC. These optional modules would be utilized when progress with psychological treatment was being impeded either at the service or patient level. The modules were as follows: i. Stigma: Techniques to address stigma associated with mental health and epilepsy-related

stigma [32] ii. Parental Mental Health: Focus groups, PDSA cycles, interviews and the literature highlighted that parenting a child with epilepsy and mental health difficulties can be stressful [33] and parental anxiety and depression were recognized as potential barriers for some families that needed to be addressed for successful implementation of the intervention. iii. Transition to adulthood: Such transition-related issues were considered as potential barriers to the implementation of the mental health intervention in this population and therefore necessary to address within the modified intervention when they arose.

Patients were offered weekly therapy sessions over 6 months, delivered either to the parent/carer, young person or both, depending on presenting difficulty, age and intellectual ability. The number of sessions offered was flexible and collaboratively decided between the therapist and family. Families received the number of sessions considered necessary to meet and sustain their goals, up to a maximum of 22. Thirteen health care professionals were trained in the intervention. They were from a range of professional backgrounds, including paediatric nurses and epilepsy nurse specialists (n=6), consultant paediatricians (n=2), psychological wellbeing practitioner (n=1) and assistant psychologists (n=4). The assistant psychologists had master's level degrees in psychology but had not previously delivered psychological therapy. The psychological wellbeing practitioner was trained specifically in low-intensity psychological therapies such as guided self-help, and did not have prior experience of delivering a full CBT therapy.

Provider training took place over six months and included a five-day intensive training led by experts in the field of epilepsy and mental health, including members of the MATCH-ADTC team, epilepsy experts and mental health professionals with extensive experience in working with children, young people and families. Topics comprised knowledge of evidence-based psychological techniques, skills in assessment, goal setting and formulation, use of routine outcome measures, and engagement and therapeutic style. The training included information about tailoring information to meet the needs of children with cognitive limitations. Therapists received a half-day booster training at the end of the six-month period with topics tailored to their individual training needs and included developing SMART goals, how to handle interference, and agenda setting. The five and a half face-to-face training days included multimethod learning with a focus on developing practical skills through skills practices and observations. All therapists subsequently saw at least one family for telephone-delivered mental health treatment during the six-month training period. All treatment sessions were recorded.

During this time, HCPs were offered weekly telephone clinical supervision with a qualified clinical psychologist, which included review of weekly routine outcome measures, progress toward patient goals, review of sections of audio-recordings of therapeutic sessions, and role-play. Clinical supervision was delivered over the telephone to match the therapeutic mode of delivery and to maximize accessibility to HCPs who were based at multiple sites in England. HCPs received between 4 and 12 telephone supervision sessions ranging between 12-63 minutes (M = 41.18 minutes SD =10.30). HCPs also had regular email contact with their clinical supervisor. All treatment sessions were recorded. HCPs followed a treatment protocol and completed an adherence checklist for each session. HCP competence in intervention delivery was assessed in a two-stage process; firstly HCPs were considered competent in delivering the

Rating Scale Revised (CTSR) with all items scoring at least two [34]. In the second stage, the completed CTSR, weekly measures and adherence checklist were sent to a MATCH-ADTC consultant, who reviewed the materials to confirm the HCP as competent in delivery of the therapy.

### 2.6. Analysis

## 2.6.1. Feasibility

The key feasibility outcomes for this phase of the research programme were: i) the extent to which HCPs could be trained to deliver the intervention to competence, defined as the proportion of HCPs reaching competence at the end of the six month training phase and ii) the extent to which participants allocated to receive the intervention completed six or more therapy sessions.

#### 2.6.2. Preliminary effectiveness

Treatment groups were descriptively compared on all baseline measures. Paired samples t-tests were used to analyse changes across time from baseline to post-treatment for the SDQ, RCADS and PedsQL for all children with pre and post-intervention data, using SPSS [35]. Significance was considered at the 0.05 level. Effect sizes (Cohen's d - the difference between the means divided by the pooled SD) calculate d to assess preliminary effectiveness. The confidence intervals for Cohen's d were calculated using the "Psych" Package in R [36]. The mean goal rating before and after therapy was calculated for each primary problem (anxiety, depression, disruptive behaviour).

### 3. Results

### 3.1. Feasibility

All 13 HCPs who completed training reached competence in delivery of the intervention according to the criteria outlined in the methods. 34 participants were allocated to receive the intervention, of whom 28 completed the intervention. Of the six who did not complete the intervention, one discontinued after the assessment (reason not given), three discontinued after one therapy session due to time commitment issues (n=2) and not being able to recontact for the second session (n=1), one discontinued after two sessions due to a family bereavement and one discontinued after 3 sessions due to the child not feeling able to concentrate during the sessions. Of these six children and young people, two had impairing behavioural difficulties, three had impairing anxiety symptoms, and one had both impairing behavioural difficulties and symptoms of anxiety. One had a diagnosed intellectual disability and one had an Autism Spectrum Disorder (ASD) diagnosis. In addition to the six participants described above who did not complete the intervention, five further participants were not able to be contacted after the intervention to complete measures. In total, twenty-three parent/carers of participants (one father, 18 mothers, one grandmother and three mother/father pairs) completed at least one measure at postintervention. The demographics of these participants are reported in Table 1. Eleven were male and the mean age was 9.63 (SD = 3.03). There were no significant differences between the demographics or baseline measure scores for those who completed at least one 6-month outcome measure compared to those who completed no 6-month outcome measures (Tables 1 & 2). The 23 participants completed an average of 8.5 therapy sessions and were treated by 11 of the 13 HCPs trained in the intervention.

### 3.1.1. Diagnoses from DAWBA (Table 3)

For the 23 participants providing at least one outcome measure at the 6 months follow-up (i.e. one of the SDQ, RCADS or PedsQL), over half met full diagnostic criteria for at least one DSM5 mental health disorder (n=14). Nine of these met criteria for one DSM5 diagnosis and five met criteria for two. The most common diagnoses were oppositional defiant disorder (ODD) (n=9) and separation anxiety (n=8).

# 3.2 Within subject effect

## 3.2.1 Mental health and quality of life measures (Table 4)

The analyses of the outcome variables from baseline to end of treatment are presented in Table 4. There was a statistically significant reduction in total symptoms and total impact on the SDQ, with corresponding medium effect sizes (Cohen's d=.62 and d=.57, respectively). Post-hoc power analysis demonstrated that the achieved power for detecting a pre-post difference in SDQ total was 0.86 at  $\alpha=0.05$ . There was also significant reduction in symptoms on the emotional symptoms and hyperactivity subscales of the SDQ, but not for the conduct, peer problems or prosocial subscales. There were significant reductions in symptoms reported on the RCADS for the total score and the Major Depressive Disorder, Generalised Anxiety Disorder, Panic Disorder and total anxiety subscales. Symptoms also reduced on the Obsessive Compulsive Disorder (OCD), separation anxiety and social anxiety subscales but these changes were not statistically significant. Scores on the PedsQL physical and emotional functioning subscales demonstrated statistically significant reductions.

#### 3.2.2 Goal based outcomes

Overall, there was a significant increase in progress towards goals between the first session (M = 3.10, SD = 1.60) and final session (M = 7.38, SD = 1.61) ratings; t(22) = 12.08, p < .001.

Separated by primary problem area, there was also a significant increase in goal rating for the 11 participants with a primary behavioural difficulty between first session (M = 3.44, SD = 1.83) and final session (M = 7.23, SD = 1.97; t(10) = 8.01, p<.001), and for the 12 participants presenting with primary anxiety symptoms, where the mean goal rating before intervention was 2.78 (SD = 1.35) and after intervention was 7.52 (SD = 1.26; t(11) = 9.36, p<.001).

#### 4. Discussion

The aim of this study was to determine the feasibility of telephone-delivered therapy for mental health difficulties embedded in paediatric epilepsy clinics delivered by people with limited training in psychological therapy during the training phase of a larger programme of research. The results of this phase of the research suggest that it was possible to successfully train these HCPs within a six month time period to deliver the CBT intervention to competence, that the majority (82%) of the 34 participants allocated to receive the intervention completed at least six sessions of the planned treatment, and that 23 of the 28 completing at least six sessions then completed follow-up measures. Patients who completed the follow-up measures showed significant reductions in parent-reported symptoms of mental health problems and improving quality of life in children and young people. This is one of the largest studies of psychological treatment for mental health problems in children with epilepsy to date [37].

The most common presenting mental health problems were separation anxiety and oppositional defiant disorder and many participants had intellectual disability. The within subject effect sizes for the 21 participants who provided pre-and post-intervention SDQ data were in the medium to large range for total emotional and behavioural symptoms and impact, as measured by the parent-reported SDQ, suggesting that the intervention has promise for treating mental

health difficulties in young people with epilepsy. Changes in symptoms on the conduct problems, peer problems and prosocial subscales of the SDQ were not statistically significant for these 21 participants. However, this is in line with previous research suggesting that these subscales are not useful in pre-post measurement [38]. In addition, whilst scores on the SDQ total and impact scales were in the 'high' and 'very high' ranges at baseline, scores on the SDQ conduct problems and prosocial subscales were in the 'close to average' to 'slightly raised' ranges and therefore a larger sample size may have been needed to demonstrate a significant effect. It is also possible that MATCH-ADTC is more effective for emotional problems in this group, however comparable significant improvement in goal progress for children with behavioural problems and emotional problems suggests that it is effective for both behavioural and emotional difficulties.

Six of 34 (18%) participants meeting inclusion criteria for the intervention completed fewer than six sessions. This is in line with other studies of treatment for mental health problems in children and young with epilepsy [39,40]. Two of the six families completing fewer than six sessions stated that the study was too time-consuming – future studies should therefore be clear about the time commitment involved. These participants may also benefit from lower intensity interventions. There was no clear pattern of presenting problems or additional difficulties in those who did not complete at least six sessions.

The study had several strengths. It is the first UK study to implement the full MATCH-ADTC modular intervention in clinical practice for common mental health difficulties in children. The study had broad inclusion criteria and as a result, many participants had an intellectual disability and many met diagnostic criteria for more than one mental health disorder. HCPs and patients were also recruited from a diverse range of settings, ranging from a national

paediatric hospital to local hospitals. The results suggest that the intervention and training models were effective in treating mental health problems across this diverse patient group.

Overall, the nature of the training and intervention enabled care that was fully integrated with the physical health treatment. Embedded specialist psychiatrists and/or psychologists improve outcomes for children and young people with chronic health conditions [41]. As a result, the 'Best Practice Tariff' for paediatric diabetes services in England mandated access to integrated psychological support. This tariff is associated with funding for services. This is not currently the case in paediatric epilepsy services. The Epilepsy12 National Clinical Audit of Seizures and Epilepsies for Children and Young People in England and Wales 2018-2019 found that few epilepsy centres were able to provide co-located mental health services for children and young people [42]. They suggested that services for children and young people with epilepsy should include sufficient integrated mental health provision, some of which should be co-located within the epilepsy clinics. The model of training and intervention by HCPs relatively inexperienced in formal CBT delivery presented in this paper should be a cost-effective and scalable to achieve such integrated provision. Many teams were previously having to provide some level of mental health support routinely due to the nature of their roles and the client group, but had no formal training and so valued having formal approaches to managing these difficulties. However, it is important to note that health providers completed a five-day training course and were supervised throughout the 6-month training period. The costs of this training and supervision will need to be accounted for in future evaluations and implementation of such models. The successful training protocol has significant potential to be disseminated and used both in other epilepsy services and for other chronic illnesses. However, a full-scale trial is needed to determine efficacy and cost-effectiveness.

Limitations of the study are primarily the uncontrolled study design and the phase of the research as HCPs were 'in training'. The uncontrolled design means that we cannot confidently attribute change in symptoms to the intervention itself. Whilst changes in the physical health subscale of the PedsQL are encouraging, indicating improved health-related Quality of Life, it may be that these were unrelated to the intervention and that coincidental improvements in physical health caused improvements in mental health. Future studies should collect data on seizure severity and frequency to determine whether physical health affects treatment outcome.

Five of the 28 patients who received six or more sessions, and all of the 6 patients who did not receive six or more sessions did not complete follow-up measures. We therefore do not know whether the intervention was effective or acceptable for these participants. Considering generalisability, only one patient was diagnosed with autism, and no patients were diagnosed with depression. We therefore cannot comment on effectiveness of the intervention for these groups. The proportions of children with autism and depression are lower than the known prevalence of both disorders in children and young people with epilepsy [43,44]. It is possible that these numbers reflect biases in study recruitment, as paediatric staff identified patients that they considered would be suitable for the intervention. Our previous screening study identified a number of young people with both depression and autism suggesting that active screening of all patients, rather than relying solely on clinician identification, may result in a sample that is more representative of the epilepsy population [45]. Several researchers and groups have advocated for targeted screening and identification programmes for children with a chronic physical illness. For example, the UK NHS Quality and Innovation (CQUIN) scheme WC3 - CAMHS Screening for Paediatric Patients with Long Term Conditions specified nationwide screening with the SDQ in patients with a chronic physical illness in children's hospitals, in order to identify their mental health needs [46]. Screening programmes have been suggested for children and young people with epilepsy specifically [31,47] and consensus statements for epilepsy advise screening for depression and anxiety [48,49].

Half of the participants did not meet diagnostic criteria for a mental health disorder according to the DAWBA, which may suggest that the study recruitment method also prevented the identification of those with the most severe symptoms. However, the mean SDQ impact score was in the very high range, suggesting that this was an impaired group of patients with symptoms warranting intervention. The study also relied on parent report but there may be differences between parent, teacher and child reports of mental health and quality of life in children with epilepsy [3,5,31]. It is possible that diagnosis rates would have been different had additional informants been considered. Finally, as each HCP treated a limited number of patients, we did not assess change in competence over time or investigate specific therapist effects.

## 4.1.Conclusions

Results suggest that a modular cognitive behavioural treatment delivered over the telephone by HCPs with limited experience of psychological intervention was feasible for treating mental health problems in children and young people with epilepsy. Mental health symptoms and aspects of Health Related Quality of Life also improved over the duration of treatment. Overall, results were encouraging and suggested that it is feasible to train clinicians who do not have significant prior experience of psychological therapy to deliver the intervention to competence within six months. Results from outcome measures indicated that the intervention has the potential to be an effective treatment, allowing progression to the definitive randomised controlled trial in the next phase of the programme of research.

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**Tables** 

 Table 1. Sample demographics and epilepsy variables.

Participants (n = 23)	Analysed (n=23)	Not Analysed (n=11)	t/χ²; p
Age (M, SD)	9.47 (2.23)	9.63 (4.37)	.14;.89
Gender			
Female	10 (43.5%)	6 (54.5%)	.06;.81
Male	13 (56.5%)	5 (45.5%)	
Diagnosis of Autism Spectrum Disorder			
Yes	1 (4.3%)	3 (27.3%)	1.88;.17
No	22 (95.7%)	8 (72.7%)	
Diagnosis of Intellectual Disability			
Yes	9 (39.1%)	2 (18.2%)	.69;.41
No	14 (60.9%)	9 (81.8%)	
Prescribed AEDs			
Mono	7 (30.4%)	2 (18.2%)	.12;>.99
Two or more AEDs	10 (43.5%	1 (9.1%)	2.60;.11
None	6 (26.1%)	8 (72.2%)	4.90;.08

**Table 2.** Comparison of baseline scores on the SDQ (Strengths and Difficulties Questionnaire), RCADS (Revised Child Anxiety and Depression Scale) and PEDSQL (Paediatric Quality of Life Inventory) in participants who were analysed verses those who were not.

			Analysed	Not analysed				
Measure	Subscale	n	Pre (SD)	n	Pre (SD)	T (degrees of freedom)	Mean difference (95% CI)	p
SDQ	Total	21	19.67 (5.75)	13	21.38 (3.64)	-0.962 (32)	-1.72 (-5.36;1.92)	.343
	Emotional	21	6.10 (2.30)	13	6.69 (2.53)	-0.708 (32)	-1.72 (-5.00;1.56)	.484
	Conduct	21	2.86 (2.31)	13	3.92 (2.06)	-1.361 (32)	-0.6 (-2.31;1.12)	.183
	Hyperactivity	21	6.43 (1.78)	13	7.00 (1.96)	-0.877 (32)	-0.6 (-2.38;1.18)	.387
	Peer	21	4.29 (2.59)	13	3.77 (2.55)	0.568 (32)	-1.07 (-2.66;0.53)	.574
	Prosocial	21	7.29 (2.59)	13	6.00 (3.27)	1.273 (32)	-1.07 (-2.63;0.49)	.212
	Impact	21	5.05 (2.85)	13	6.31 (2.18)	-1.363 (32)	-0.57 (-1.90;0.76)	.183
RCADS	MDD	20	69.68 (15.50)	12	62.26 (22.81)	-1.098 (30)	-7.42 (-21.23;6.39)	.281
	GAD	19	59.67 (17.55)	12	50.84 (10.47)	-1.57 (29)	-8.83 (-20.34;2.67)	.127
	OCD	20	52.39 (12.28)	12	51.26 (10.19)	-0.268 (30)	-1.13 (-9.75;7.49)	.790
	PD	19	62.75 (15.42)	12	55.60 (14.68)	-1.282 (29)	-7.16 (-18.58;4.26)	.210
	SAD	20	67.14 (16.44)	12	65.01 (20.21)	-0.324 (30)	-2.12 (-15.48;11.24)	.748
	Soc	19	55.53 (13.67)	12	53.54 (17.01)	-0.361 (29)	-2.00 (-13.33;9.33)	.721
	Anxiety	19	62.58 (15.76)	12	55.94 (15.70)	-1.144 (29)	-6.64 (-18.51;5.23)	.262
	Total	19	65.37 (16.53)	12	58.86 (15.37)	-1.096 (29)	-6.51 (-18.65;5.63)	.282
PEDSQL	Physical	22	58.64 (24.82)	10	55.52 (26.08)	-0.322 (30)	-3.12 (-22.93;16.691)	.750
	Emotional	22	45.97 (15.52)	10	49.50 (17.23)	0.577 (30)	3.53 (-8.97;16.04)	.568
	Total	22	53.71 (19.46)	11	52.80 (19.68)	125 (31)	-0.90 (-15.61;13.81)	.901

Note: SDQ = Strengths and Difficulties Questionnaire; RCADS = Revised Child Anxiety and Depression Scale; MDD = Major Depressive Disorder; GAD = Generalised Anxiety Disorder; OCD= Obsessive Compulsive Disorder; PD= Panic Disorder; SAD= Separation Anxiety Disorder; Soc= Social phobia; PEDSQL = Paediatric Quality of Life Inventory; sd= Standard Deviation; CI = Confidence Intervals

#### **Clinical cut-points of measures:**

SDQ Total difficulties score: 0-13 = close to average, 14-16 = slightly raised, 17-19 = high, 20-40 = very high

SDQ Emotional problems score: 0-3 = close to average, 4 = slightly raised, 5-6 = high, 7-10 = very high

SDQ Conduct problems score: 0-2 = close to average, 3 = slightly raised, 4-5 = high, 6-10 = very high

SDQ Hyperactivity score: 0-5 = close to average, 6-7 = slightly raised, 8 = high, 9-10 = very high

SDQ Peer problems score: 0-2 = close to average, 3 = slightly raised, 4 = high, 5-10 = very high

*SDQ Prosocial score*: 8-10 = close to average, 7 = slightly lowered, 6 = low, 0-5 = very low

SDQ Impact score: 0 = close to average, 1 = slightly raised, 2 = high, 3-10 - very high

RCADS: 65 = borderline clinical threshold, 70 = clinical threshold

 Table 3. Diagnoses from DAWBA (Development and Wellbeing Assessment)

DSM-5 Diagnosis	Frequency (%)
Separation Anxiety	8 (40)
Social Phobia	1 (5)
ADHD Combined	1 (5)
ODD	9 (45)
PDD/autism	1 (5)
Primary target of intervention	
Anxiety	7 (30)
Depression	2 (9)
Disruptive behaviour	14 (61)
Number of diagnoses	
0	9 (39)
1	8 (35)
2	6 (26)

Note: DSM-5= Diagnosis and Statistical Manual of Mental Disorders-5; ADHD = attention deficit hyperactivity disorder; ODD = oppositional defiant disorder, PDD= pervasive developmental disorder

**Table 4.** Outcomes on mental health and quality of life measures

	Subscale	Pre (SD)	Post (SD)	T (degrees of freedom)	Mean difference (95% CI)	p	d
SDQ (n=21)	Total	19.67 (5.75)	14.90 (7.75)	2.829 (20)	4.76 (1.25;8.27)	.01**	.62 (02;1.25)
,	Emotional symptoms	6.10	4.29	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	1.81	<.01**	.68
	<i>J</i> 1	(2.30)	(2.83)	3.120 (20)	(0.60;3.02)		(.03;1.31)
	Conduct problems	2.86	2.29	` /	0.57	.19	.29
	•	(2.31)	(2.37)	1.351 (20)	(-0.31;1.45)		(32;.90)
	Hyperactivity	6.43	4.90	` ,	1.52	.03*	.52
		(1.78)	(2.72)	2.386 (20)	(0.19; 2.86)		(11;1.14)
	Peer problems	4.29	3.43	` /	0.86	.13	.35
	1	(2.59)	(2.46)	1.600 (20)	(-0.26;1.98)		(27;.96)
	Prosocial	7.29	7.48	` '	-0.19	.52	.14
		(2.59)	(2.99)	-0.658 (20)	(-0.80;0.41)		(47;.74)
	Impact	5.05	3.29	` ,	1.76	.03*	.52
	4	(2.85)	(3.04)	2.392 (20)	(0.23;3.30)		(11;1.14)
RCADS	MDD (n=20)	69.68	60.37	3.118 (19)	9.31	<.01**	.70
(n=20)	,	(15.50)	(15.76)	` '	(3.06;15.55)		(.03;1.35)
,	GAD(n=19)	59.67	51.98	3.739 (18)	7.70	<.01**	.86
	,	(17.55)	(13.55)	` '	(3.37;12.02)		(.15; 1.54)
	OCD(n=20)	52.39	48.45	1.891 (19)	3.93	.07	.42
	PD (n=19)		(6.68)	` ,	(42;8.29)		(22;1.04)
			55.93	2.171 (18)	6.82	.04*	.50
		(15.42)	(13.94)	` ,	(.22;13.43)		(16;1.15)
	SAD (n=20)		59.82	1.970 (19)	7.31	.06	.44
	,	67.14 (16.44)	(15.75)	` /	(46;15.08)		(20;1.07)
	Soc (n=19)	55.53	52.81	.792 (18)	2.73	.44	.18
	,	(13.67)	(12.93)	` ,	(-4.51;9.97)		(46;.82)
	Anxiety $Total (n=19)$	62.58	55.21	2.296 (18)	7.37	.03*	.53
		(15.76)	(13.48)	` ,	(6.30;14.12)		(14;1.18)
	<i>Total (n=19)</i>	65.37	57.09	2.496 (18)	8.28	.02*	.57
	,	(16.53)	(14.67)	` /	(1.31;15.24)		(10;1.22)
PedsQL	Physical Functioning	58.64	69.95	-2.177(21)	-11.30	.04*	.46
(n=22)		(24.82)	(27.67)	` '	(-22.10;50)		(-1.00; 1.91)
` /	Emotional Functioning	45.97	58.86	-2.652(21)	-12.90	.02*	.57
		(15.52)	(24.10)	` '	(-23.01;2.78)		(89;2.02)
	Total	53.71	65.71	-2.694(21)	-12.00	.01**	.57
		(19.46)	(23.77)	` '	(-21.27;2.74)		(89;2.02)
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Note: SDQ = Strengths and Difficulties Questionnaire; RCADS = Revised Child Anxiety and Depression Scale; MDD = Major Depressive Disorder; GAD = Generalised Anxiety Disorder; OCD = Obsessive Compulsive Disorder; PD = Panic Disorder; SAD = Separation Anxiety Disorder; Soc = Social phobia; PEDSQL = Paediatric Quality of Life Inventory; sd = Standard Deviation; CI = Confidence Intervals

**Figure 1.** CONSORT Diagram of participant flow.

