



RESEARCH ARTICLE

REVISED Usual care for mental health problems in children with epilepsy: A cohort study [version 2; peer review: 2 approved]

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Abstract

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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REVISED Amendments from Version 1

In response to the reviewer's comments and suggestions, we have made some clarifications to the methodology section and have included a flowchart to supplement this information. We have also made some changes to the discussion, particularly with regard to the limitations of the study, and have reviewed our conclusions in light of these.

Any further responses from the reviewers can be found at the end of the article

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 (Rodenburg *et al.*, 2005) and of children with other Long Term Conditions, such as diabetes (Davies *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). The aim of the feasibility study was to obtain information on key variables needed for a fully powered randomised controlled trial of screening and intervention for mental health problems in children with epilepsy. Specific objectives were to obtain estimates of:

- recruitment rates
- willingness of participants to be randomised
- willingness of clinicians to recruit participants
- time needed to obtain consent, collect and analyse data
- completion rates for the measures
- the nature of treatment as usual

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). The full details of this procedure are published elsewhere (Bennett *et al.*, 2019).

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. Participants were a mixture of new referrals and children who had been regularly attending epilepsy clinics. 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). The SDQ has been used and validated across the age range of those attending paediatric neurology clinics (e.g. Glazebrook *et al.*, 2003) and used in children with intellectual disabilities (Kaptein *et al.*, 2008) and autism spectrum disorder (Iizuka *et al.*, 2010), both of which are common comorbidities in children with neurological conditions such as epilepsy (Reilly *et al.*, 2014). Those who met threshold for significant emotional or behavioural symptoms were asked to complete the full age corresponding version of the Development and Well-being Assessment (DAWBA), an online clinical assessment designed to generate psychiatric diagnoses (Goodman *et al.*, 2000). In addition to the computer generated diagnoses, the DAWBA was 'hand' rated by a qualified clinical psychologist who had training in DAWBA rating. Caseness on the SDQ was defined as the combination of raised symptom score (≥ 14 out of a maximum of 40) and raised impact score (≥ 2 out of a maximum of 10; Goodman *et al.*, 2002). The psychometric properties of measures such as the SDQ and DAWBA are

well established within paediatric clinic samples, particularly epilepsy clinics (Hanssen-Bauer *et al.*, 2007; Hysing *et al.*, 2007). 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) (Welch, 2020). This questionnaire was completed electronically by participants. Participants were not offered any specific interventions or referrals for intervention.

As shown in the flowchart (Figure 1), of those attending clinics, 225 participants completed the SDQ and 121 (54%) of these reached caseness on the SDQ. Of the 121 participants 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.

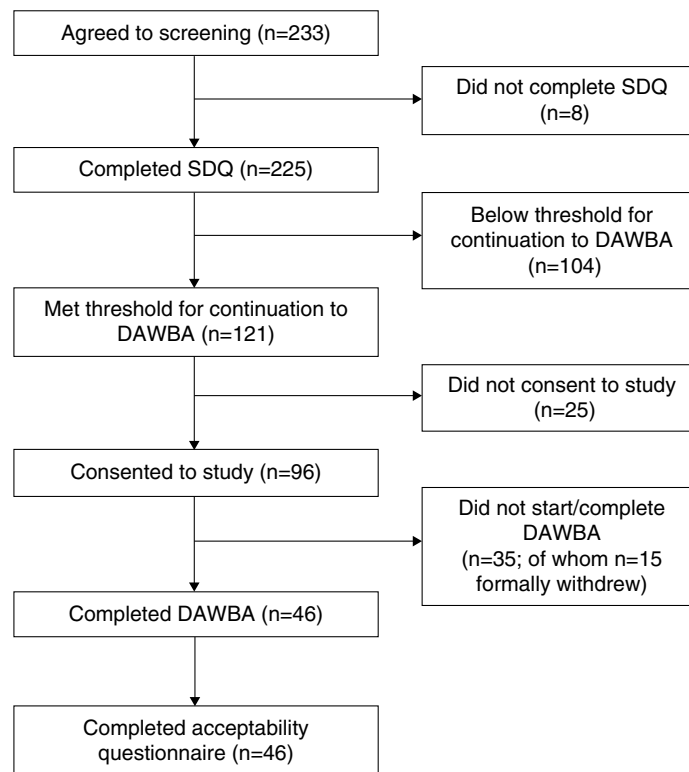


Figure 1. Flowchart of study participation. DAWBA, Development and Well-being Assessment; SDQ, Strengths and Difficulties Questionnaire.

Data analysis

Data was extracted and coded from the Experience of Support questionnaire by a 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 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](#);

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

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 attributed 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, we acknowledge there are limitations to this study with regards to the sample. The sample size of 46 is small and does not account for the proportion of children with epilepsy within the UK that do not attend paediatric epilepsy clinics – often those with less complex epilepsy. Given these limitations, it is important to note that our findings only apply to a select population of children with epilepsy. 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. We recognise that NICE guidelines should serve as a basis for treatment recommendations and therefore, future studies may benefit from considering the additional, contextual factors that may influence the family and health professional's treatment decisions. Similarly, it would have been valuable to obtain the reasons why some families did not complete the DAWBA as there is a possibility that a proportion of these families may have been receiving mental health treatment and therefore not felt the need to proceed which, if so, would influence the findings. Finally, there was no control group of children without epilepsy so it not possible to determine whether this problem is

specific to children with epilepsy. 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. However, in light of the limitations discussed above, it is difficult to estimate the size of this clinical problem. 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.

Extended data

Supplementary File 1: Experience of Support Questionnaire. <https://doi.org/10.6084/m9.figshare.11907747.v1>

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Maria Teresa Lax-Pericall

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My previous comments have been addressed and, in my opinion, it can be approved.

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 14 April 2020

<https://doi.org/10.5256/f1000research.24840.r62182>

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Charlotte U. Rask 

Department of Child and Adolescent Psychiatry, Aarhus University Hospital, Aarhus, Denmark

Thank you for the opportunity to re-review the revised paper where the authors have comprehensively addressed the concerns and points of clarification from the first review.

Just a minor comment:

This sentence should be deleted in the section on procedures and only reported in the result section (where it is already stated):

..."of these 29 (63%) met diagnostic criteria for at least one DSM5 disorder".

Competing Interests: No competing interests were disclosed.

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

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 07 May 2019

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This study addresses the important question whether children with epilepsy who have mental health difficulties are appropriately identified and managed. It concludes that there is “*inconsistency and inadequacy of mental health provision for children and young people with epilepsy*”. In the discussion the authors add “This study revealed that the majority of young people with mental health needs in epilepsy services were not receiving any intervention” and that “a large gap in mental health provision exists within this group”. The authors mention the “inadequacy” of some of the interventions received by some of the 16 children.

The study was conducted in 6 different paediatric epilepsy clinics, covering a large geographical area over 6 months; therefore should be well placed to address the issue of possible variability and inconsistency in accessing mental health services and treatments provided. However, there are some limitations to the methodology of this study that may influence the conclusions the authors have reached.

Methodology

Sample bias: The study was conducted as part of a feasibility study carried out in paediatric epilepsy clinics. Not all children with epilepsy in the UK are seen in a paediatric epilepsy clinic, there is a proportion of children with epilepsy (in the UK these usually are children with less complex epilepsy) that are seen by general paediatricians. Therefore, it should be clear that the findings apply to a selected population of children with epilepsy (probably children with more complex epilepsy). The authors made this clear in the abstract, but because the frequency of mental health problems is higher in children with epilepsy who have other neurological conditions or changes in the MRI than in children with less complex epilepsy, I think it would be worth marking this point in the discussion.

The next issue is that we are told that the SDQ was completed as part of routine practice and that there were 121 SDQs that screened positive. It would be useful to know the total number of patients and the percentage of SDQs completed out of the total number of patients. It could be that not all potential participants completed the SDQ. If the ones that did not complete the SDQ are the parents whose children had mental health problems and are receiving appropriate treatment. I must say that, from a

clinician's perspective this explanation seems unlikely, but the paper is research and therefore this possibility needs to be mentioned as a limitation because it will affect the conclusions reached.

The next issue is that of 121 cases with positive screen in the SDQ only 46 completed the DAWBA. It is impossible to know why more than 50% of parents did not complete it. Could it be because at least some of them are receiving treatment and are improving? If these were the case it would certainly affect the conclusions. It may not be possible to know this now, but this should be mentioned in the discussion as a limitation.

Discussion

There is not a section regarding **limitations** of the study and, in my opinion, there should be, with the conclusions reviewed taking into account the limitations.

The authors talk about the inadequacy of some of the interventions received by the 16 children. They take NICE guidelines as "gold standard". Although, in my opinion, this is a good starting point, there are many disorders for which NICE does not have specific recommendations and, even if there was a guideline for a condition, we do not treat conditions, we treat children. Therefore, one cannot conclude that a treatment given was "inadequate" without knowing much more about that particular child, family and other factors that may influence the decision regarding treatment offered...

Suggestions

The study will benefit from a limitations section in the discussion and reviewing /curtailing their conclusions in the light of these.

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?

Partly

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

No source data required

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Mental health difficulties in children with epilepsy and brain injury

I confirm that I have read this submission and 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.

Author Response 11 Feb 2020

Alice Welch, Mayo Clinic, London, UK

Thank you very much for your extremely helpful comments and suggestions. We have made the following changes and clarifications to the methodology and discussion:

- We have included further recruitment data to highlight the proportion of participants that completed the SDQ. As suggested, we have also added a flowchart to supplement this information (See Figure 1).
- We have added to our limitation section within the discussion to consider your point re NICE guidelines as the 'Gold standard', limitations to the sample and lack of further information re DAWBA completion. We have reviewed our conclusions in light of these.

Competing Interests: No competing interests were disclosed.

Reviewer Report 31 January 2019

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Charlotte U. Rask 

Department of Child and Adolescent Psychiatry, Aarhus University Hospital, Aarhus, Denmark

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 confirm that I have read this submission and 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.

Author Response 11 Feb 2020

Alice Welch, Mayo Clinic, London, UK

Thank you very much for your extremely helpful comments and suggestions. We have made the following changes and clarifications to the methodology:

- We have provided further detail on the design and objectives of the feasibility study.
- We have clarified how the DAWBAs were clinically rated and provided further detail regarding the use of the SDQ within paediatric clinical samples.
- We have included further recruitment data to highlight the proportion of participants that completed the SDQ. As suggested, we have also added a flowchart to supplement this information (See Figure 1).

Competing Interests: No competing interests were disclosed.

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