

Guided self-help for mental health disorders in children and young people with chronic neurological conditions: A qualitative evaluation

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Abstract

Objective

Children with neurological conditions such as epilepsy are at high risk of developing mental health disorders. Guided self-help can be used to increase access to psychological therapies. When developing and evaluating interventions, it is important to obtain the views of service-users about their acceptability. A telephone-guided self-help intervention was used to treat common mental health difficulties in children and young people with neurological conditions. The intervention was not adapted in content to account for chronic illness. This study therefore reports on qualitative interviews with participants to determine the acceptability of the intervention.

Methods

Semi-structured interviews were conducted with 27 participants (25 parents and 2 young people) who had undertaken a telephone-delivered guided self-help intervention for common mental health difficulties in the context of a paediatric neurological condition. Transcripts were analysed thematically using the framework approach.

Results

Thirteen themes were extracted, organised into three main domains, which covered: the practicalities of telephone guided self-help treatment; the outcomes of the intervention; and the extent to which adaptation was needed for chronic illness. Most families found the intervention helpful in working towards their specific goals and noticed changes for the child and/or parents and family.

Conclusions

Participants had a positive experience of the intervention and the majority of parents found the standard intervention with individualised goals sufficient to meet the young person's mental health needs.

Introduction

Children and young people with chronic neurological conditions, such as epilepsy, are significantly more likely to experience a mental health problem than children who are otherwise physically well – 50% or greater compared with 10%.¹ Numerous studies have demonstrated the negative impact of mental health disorders on outcomes for children with epilepsy, and national guidelines promote their detection and treatment.² Despite the guidance, ‘contemporary standards of practice fail to integrate screening and treatment of the comorbidities into routine clinical care’ (p.1).³ For example, one study found that whilst on screening, 60% of the 114 children with epilepsy met criteria for a diagnosis of a mental health disorder according to the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV), over 60% of these had never had any contact with a mental health professional.⁴

There are a number of possible factors that may contribute. For example, in neurology, there may be a lack of capacity, diagnostic overshadowing by the chronic physical illness, an assumption that the mental health disorders are not treatable but instead a permanent aspect of the neurological condition, or that that the mental health disorders will only respond to epilepsy treatment or will resolve after the neurological condition has been treated. Within mental health services, mental health clinicians may feel ill-equipped to deal with the physical illness (for example fear of provoking a seizure) or believe current evidence-based treatments for single disorders are inadequate for patients with multiple morbidities (including neurological and neurodevelopmental).

Research on the treatment of mental health disorders in the context of neurological conditions such as epilepsy has been criticised as ‘embarrassingly rare’.³ A recent systematic review of psychosocial interventions for children and young people with epilepsy found several studies of interventions aimed at improving understanding of epilepsy and quality of life⁵ but only two studies (one with a follow-up paper) were aimed at children and young

people meeting pre-specified thresholds of mental health difficulties.⁶⁻⁸ The first of these studies used a computerised, standard cognitive behavioural intervention to address anxiety in young people with epilepsy and the intervention had a positive impact.⁶ The second study⁸ used a cognitive behavioural intervention to reduce symptoms of depression. The two studies give encouragement that standard psychological treatments are effective for mental health disorders in the context of neurological illness. No studies to date have addressed the impact of intervention for disruptive behaviour disorders in children with neurological conditions, despite their high prevalence in this group.⁹

Due to the lack of available research, there is little formal direction as to which assessments and interventions should be used by clinicians for this group.⁷ In the absence of official guidance, there is debate regarding the types of assessments and interventions that should be used to identify and treat mental health difficulties in children with neurological conditions, and in particular, the amount of adaptation required to account for the presence of physical illness. Wagner and Smith¹⁰ suggest that in the absence of ‘epilepsy-specific psychological assessment and intervention tools’, clinicians should use evidence-based interventions with routine outcome measurement, and that ‘research to develop standardized psychosocial evaluation tools and treatment protocols in the pediatric epilepsy clinic should be paramount and a high priority of researchers in the field’. Jones and colleagues⁷ advocate similarly, and additionally suggests that future research into the treatment of mental health problems in children with epilepsy may inform future patient centred outcomes/individualized therapy (cf. Beidas¹¹), through investigating the impact of seizures, co-occurring neurodevelopmental disorders or learning problems on outcome in therapy.

It may be that therapies need not be adapted at all for the presence of physical illness. Heyman and colleagues¹² suggests that it is possible to intervene with mental health problems in children with neurological conditions in the same way as children who do not have

neurological conditions, and that there is no reason to suggest that medications are preferable in children with neurological conditions. Cottrell¹³ further suggests that it may not be desirable to focus on adapting treatment for one particular illness as this may lead to focus on services for one type of illness and accordingly an absence of services for others. He states that ‘there is no logical reason why the treatments known to be effective already for children’s emotional and behavioural problems should not also be effective in the presence of chronic illness’ (p. 303).

However, even if such treatment was available, would patients from neurology clinics access them? Costs, time and transport are frequently cited reasons for not accessing mental health treatment,¹⁴ and such barriers are likely to be greater for families of children with chronic illnesses.¹⁵ Morawska, Calam and Fraser¹⁶ suggest that behavioural interventions conducted with families of young people with chronic illness should be delivered in conjunction with appropriate medical management and ideally delivered in the context of the physical health care (e.g. through the same clinic/hospital). It is also recommended that the interventions are ‘as brief as possible and delivered in a cost-effective manner’ as families will already have significant intervention for the physical illness itself and therefore be time-pressured and under stress. Similarly, Santucci, Thomassin, Petrovic and Weisz¹⁷ recommend that to optimize uptake and applicability of child and adolescent mental health interventions in clinical settings, interventions should be designed ‘to fit the context of youth’s treatment’.

One effective and brief approach to meeting a large unmet need is through the use of guided self-help therapies, which involve patients completing a computerised or written self-help programme, with minimal contact/guidance from a therapist, over the telephone or email.¹⁸ This is related to, but distinct from, teletherapy or e-therapy in which telephone or technology may be used to deliver the intervention, but contact time with a therapist is not reduced in comparison to standard treatments.¹⁹ In adults, it is as efficacious as face-to-face

therapy for depression and anxiety²⁰ and is effective in adults with physical illness.²¹ One small study has examined the efficacy of a self-help parenting intervention, without guidance from a therapist, for children with chronic illness (asthma), but no participants completed the intervention.²² Several meta-analyses have demonstrated that interventions guided by a therapist (guided self-help) generally have larger effect sizes than comparable self-help treatments that are not guided by a therapist.^{23,24}

We undertook a preliminary trial of a modular guided self-help intervention for mental health disorders in a population of children and young people with chronic neurological conditions. The guided self-help intervention used was based on the Modular Approach to Therapy for Children with Anxiety, Depression, Trauma, or Conduct Problems (MATCH-ADTC).²⁵ This combines modules for the cognitive behavioural treatment of anxiety, depression, behaviour problems and trauma, taken from known evidence-based protocols, with an empirically derived algorithm for making decisions regarding which module should be used and when. For the purposes of this study, only conduct, anxiety and depression modules were used. There is a default sequence for each primary problem, but if another difficulty interferes with this (for example low mood or anxiety interferes with progress in the behaviour module) then this sequence can be amended in accordance with the empirically-derived flow chart. MATCH-ADTC has demonstrated efficacy,²⁶ and is based on standard evidence-based protocols ('Coping Cat' for anxiety,²⁷ 'Primary and Secondary Control Enhancement Training' for depression,²⁸ 'Defiant Child' for disruptive behaviour disorders²⁹). Although the full MATCH-ADTC protocol has not previously been used as guided self-help, it was chosen for the present study because it enables multiple mental health disorders to be dealt with within one intervention and so can address the high rates of comorbidity in children and young people with neurological conditions.⁹ Consistent with previous research,³⁰ the intervention was not adapted in content to account for the chronic

illness. Instead, the decision was made to use an ‘unadapted’ version, and then adapt if necessary on the basis of quantitative and qualitative results.

The present paper reports on the qualitative analysis of the study, the quantitative analyses, with results from symptom-based and diagnostic measures are reported elsewhere.³¹ It was considered desirable to assess the impact qualitatively to more fully understand the impact of the intervention on families and young people, and to ensure their views are incorporated into the design of a planned full scale study.³² We were particularly interested in exploring (i) the acceptability of a guided self-help intervention in this group, (ii) the impact that the intervention made to daily life, and (iii) views regarding the extent to which the standard intervention may need adapting to account for the chronic illness.

Methods

Procedure

All children/young people aged 7-18 attending neurology clinics and their parents were sent information leaflets about a randomised controlled pilot trial of guided self-help for mental health problems prior to attending the clinic. When in clinic, they were approached by a research assistant, who invited the parents/carers, and young person where appropriate, to complete the Strengths and Difficulties Questionnaire (a measure of emotional and behavioural difficulties) online on a tablet computer within the clinic. Informed consent and/or assent (dependent on age and ability level) was given for the full study at this point. Those scoring above a pre-specified threshold (raised symptom score of 14 or higher and raised impact score of 2 or higher) were automatically invited by the system to progress to the full diagnostic assessment questionnaire (the Development and Wellbeing Assessment), which was completed by the parent/carer at home.

Those meeting inclusion criteria were called by a researcher and invited to attend the

clinic for a face-to-face assessment appointment to confirm eligibility for the intervention. Participants attended the initial assessment in person to maximise engagement.³³ One family was offered an assessment over Skype due to logistical difficulty of attending the clinic. Families were then randomly assigned to 12 weeks of telephone-guided self-help or 12 weeks on a waiting list. Participants in the waiting list control condition were offered to participate in the guided self-help intervention following 12 weeks on the waiting list.

The Development and Wellbeing Assessment was completed prior to the intervention. Self/parent-report symptom measures were completed at baseline and following intervention for all participants. Weekly symptom trackers and goal-based outcomes were completed during the intervention.

Inclusion criteria

Inclusion criteria were: a child /young person aged 7-18, attending a neurology clinic at the study hospital, with impairing symptoms of a common mental health disorder, as indexed by either i) meeting diagnostic criteria for one or more (DSM-IV or DSM-5) mental health disorders according to clinical rating on the DAWBA, and/or ii) having a high probability of meeting criteria for at least one mental health disorder according to the computerised DAWBA algorithm results. Participants needed to be able speak/understand English sufficiently well to be able to access the intervention (as the intervention was primarily delivered to parents in the majority of cases, in practice this criterion related to the parents). Participants receiving regular ongoing intervention for the mental health disorder were excluded, as were those with high levels of risk, for example any who had significant suicidal ideation.

Ethics

This study received ethical approval from Camden and Islington NHS Research Ethics Committee, registration number 14.LO.1353. All participants provided written informed consent after reading information sheets and being given the opportunity to ask questions.

Intervention

The guided self-help intervention is based on the Modular Approach to Therapy for Children with Anxiety, Depression, Trauma, or Conduct Problems (MATCH-ADTC).²⁵ This combines modules for the cognitive behavioural treatment of anxiety, depression, behaviour problems and trauma, taken from known evidence-based protocols, with an empirically derived algorithm for making decisions regarding which module should be used and when. For the purposes of this study, only conduct, anxiety and depression modules were used. There is a default sequence for each primary problem, but if another difficulty interferes with this (for example low mood or anxiety interferes with progress in the behaviour module) then this sequence can be amended in accordance with the empirically –derived flow chart. This enables multiple mental health disorders to be dealt with within one intervention which is particularly useful as there are high rates of comorbidity in children and young people with epilepsy.⁹ In order to maximise future accessibility to treatment and cost-effectiveness, we used the MATCH-ADTC protocol as a guided self-help intervention. Guided self-help has been demonstrated to be as efficacious as standard face to face therapy (e.g. Cuijpers et al., 2010³⁴; Bennett et al., submitted³⁵).

In the first session, participants determined their top three goals for treatment, and this, along with the diagnostic results from the DAWBA, and clinical assessment, guided the choice of the starting module from the MATCH-ADTC protocol. Relevant worksheets from the MATCH-ADTC protocol, without adaptation, were sent to parents weekly, via email.

Each worksheet or set of worksheets focused on a different strategy contained within the protocol (e.g. one-to-one time for behavioural problems, constructing a graded hierarchy for anxiety, increasing pleasurable activities for depression). Participants received ten telephone or skype calls, which averaged half an hour in length, over 12 weeks, plus two follow-up calls to at one month and three months post-intervention to assess progress and troubleshoot difficulties. This is shorter than the average of 16 50-minute sessions in the standard face to face delivery of MATCH-ADTC. As a guided self-help intervention, the purpose of these phone calls was to briefly discuss the new worksheets for the week, and to discuss the implementation of the previous week's strategy as well as solve any problems that had occurred during the week. If appropriate, participants could repeat the week's strategy rather than introducing a new one, until the strategy was implemented reliably.

It is important to note that although the treatment was not adapted or changed to address neurological conditions, the intervention was tailored to the individual needs. For example, a child with a neurological condition was fearful of falling down stairs and therefore would avoid them where possible. Their goal was to be able to walk down them when safe and appropriate (e.g. not at busy times of the day) and the anxiety module was used as the primary intervention. The therapists liaised appropriately with the medical team to ensure that the goals were within safe limits, but the same basic structure of anxiety sessions and strategies discussed were used, including building a hierarchy, graded exposure, and overcoming anxious thoughts.

The MATCH-ADTC protocol is inherently flexible to family's needs and therefore was suitable for the range of participants included in the study. So, for example, for a young child with an intellectual disability and behavioural difficulties, the intervention would be primarily based on the behaviour module, and delivered via the parents, who would be the recipients of the telephone guidance. For an older adolescent without an intellectual

disability, with anxiety or depression, the intervention would be delivered to the young person and they would be the recipients of the phone call. For children and young in the middle age-range, and older adolescents with intellectual disabilities, the intervention usually involved both the child/young person and parents. Decisions regarding the recipient of the guidance were made collaboratively between the family and therapist. The content in the MATCH worksheets is at a basic level and did not need to be adapted for the presence of intellectual disability. The intervention was delivered by qualified clinical psychologists and adherence to the protocol was rated by blind independent raters.

Interview participants

The intervention was initially piloted with four participants with neurological conditions and a further 34 were randomised in the trial. All participants who had participated in the pilot and trial were approached to be interviewed. 25 parents and 2 young people agreed to be interviewed following the intervention. Of the 13 who either declined to participate in the interview, or did not respond to the invitation, 9 had not completed the therapy. We interviewed participants from 22 of the 27 families who completed therapy, 2 out of the 7 families who started but did not complete therapy and 1 family of the 4 that did not start therapy). Figure 1 outlines the flow of participation in this qualitative study.

Figure 1. Flowchart of participation in qualitative interviews.

The characteristics of the participants are detailed in Table 1. 23 of the young people had epilepsy. The presence of intellectual and/or developmental disability is noted in the table. A number of other complexities were also present in participants, including hemiplegia, memory dysfunction, speech and language difficulties, specific genetic syndromes associated

with epilepsy and or intellectual disability, executive dysfunction, partial sightedness, and many had undergone neurosurgery. These details have not been included in the table to preserve anonymity.

Table 1. Participant characteristics.

		Anxiety (N = 7)	Oppositional Defiant Disorder (N = 17)	Depression (N = 3)	Total (N = 27)
Mean age at randomisation (SD)		14.1 (3.48)	10.3 (3.09)	14.0 (5.82)	11.5 (3.8)
Males		5	9	0	14
Interviewee	<i>Young person</i>	2	0	0	2
	<i>Parent</i>	5	17	3	25
Additional factors	<i>Autism Spectrum Disorder</i>	2	8	1	11
	<i>Intellectual Disability</i>	3	11	1	15
	<i>Attention Deficit Hyperactivity Disorder</i>	0	1	0	1
Strengths and Difficulties Questionnaire total mean score	<i>Pre- intervention</i>	21.29 (very high)	22.24 (very high)	18.33 (high)	20.62 (very high)
	<i>Post- intervention</i>	16.86 (slightly raised/high)	18.60 (high)	16 (high)	17.15 (high)
Completed intervention (9/10 sessions)	<i>Yes</i>	6	15	3	24
	<i>No</i>	1 (5 sessions completed)	2 (2 sessions and 0 sessions completed)	0	3

Interviews

Following focus groups with young people and their parents (which were undertaken as part of the Public and Patient Involvement aspect of the related study regarding routine

detection and not research in their own right), a semi-structured interview was developed for the study. The focus groups provided information about important aspects to cover in the interviews. The interview was developed in an iterative cycle through discussion and feedback with study team members. The interview was piloted with a parent and young person and found to be suitable for the study requirements, therefore no changes were made to the interview schedule and this pilot data is aggregated with the full dataset.

Interviews covered participants' experiences of: the detection process; the intervention itself, including the extent to which it met the child's needs or required adaptation; the study procedures; previous experiences of accessing and receiving support for the difficulties; the relationship between mental and physical health. Both positive and negative aspects of the intervention and study procedures were elicited. Each area had stem questions, with probes that could be used if further information required. The interview ended with questions regarding the interview process and all participants were given the opportunity to state if the interview had missed any important factors that they wished to discuss.

Interviews were conducted following the intervention by three research assistants who were neither involved in the treatment nor the independent diagnostic rating of the participants conducted interviews. Consistent with the approach of the study and intervention, all interviews were conducted over the telephone to maximise ability to participate and minimise disruption for participants. Where interviews were conducted with the young person and parent from the same family, interviews were conducted separately by the parent and young person, and their answers were considered separately in the analysis. Interviews were transcribed verbatim by research assistants.

Analysis

The transcripts were analysed using the 'framework' approach.^{36,37} The first stages of

analyses were undertaken by research assistants (SG and MC), who were otherwise independent of the research study. They were supervised by SB, the primary therapist on the trial. All researchers read all transcripts thoroughly and listened to recordings to familiarise themselves with the data. They then recorded their initial comments in the transcript margins, before developing initial codes from the data, coding each line initially. ‘In vivo’ codes,^{36,37} using participants’ own words, were used wherever possible. A coding index was then developed under supervision of SB and AC, by grouping similar codes, which was then applied to all transcripts by SG and MC. Thematic charts summarising the data from each interview were then developed. The final stage was to identify patterns within these charts to develop a set of domains themes, and subthemes through collating similar codes. The study used a consensus approach and different interpretations of the data were considered throughout through discussions with senior members of the research team. Accounts of themes were developed with direct quotations to ensure that interpretations were grounded in the data. Domains, themes and subthemes were discussed amongst the research team and amended in an iterative process until a final consensus was reached.

Respondent validation was conducted to ensure that the researchers’ understanding of the participants’ interview was accurate. Participants were sent summaries of the main themes within their interview and asked whether they agreed and/or had anything to add to the summary. The participants who responded said that they agreed with the summary and the themes did not change as a result of respondent validation.

Results

The majority of participants had positive experiences of both the intervention and study procedures. Of those who had previous experience of therapy, either through local Child and Adolescent Mental Health Services, or self-help, all stated a preference for the

guided self-help intervention. All participants would recommend the intervention to other parents/young people. There were mixed opinions regarding the importance of therapists' knowledge of the physical health condition – some families felt that it was important that the therapist knew about epilepsy, whilst others did not.

Domains, Themes and Subthemes

Thirteen themes were extracted, organised into three main domains: 'Experience: the good, the bad and the support'; 'Surprises: small changes, hard work but big impact'; and 'knowing me'. The 13 themes are described below, exemplified with quotes from participants. Table 2 demonstrates which domains/themes/subthemes were pertinent to which groups of participant/s. Tables 1 and 2 demonstrate that domains, themes and subthemes applied across the full range of participants, including participants with different primary diagnoses and those with additional factors, such as intellectual disability or Autism Spectrum Disorders. There was no apparent pattern of experience according to these factors – parental comments for children with autism and intellectual disability were not noticeably different from those parents of children without such additional difficulties.

Figure 2. Domains and themes.

Table 2. Domains, themes and sub-themes in each participant group.

		ODD (N = 17)	Anxiety and Depression (N=10)	Total (N = 27)
Domain 1:				
1.1 Overall Experience	<i>Positive Experience</i>	16 (94%)	10 (100%)	26 (96%)
	<i>Negative Experience</i>	1 (6%)	1 (10%)	2 (7%)
1.2 Specific Ideas	<i>Suggestions that work</i>	12 (71%)	6 (60%)	18 (67%)
	<i>Suggestions that didn't work</i>	4 (24%)	2 (20%)	6 (22%)
1.3 Practicalities		15 (88%)	8 (80%)	23 (85%)
1.4 Stepped Care		12 (71%)	8 (80%)	20 (74%)
1.5 Better than doing it yourself		7 (41%)	5 (50%)	12 (44%)
1.6 Importance of the therapist	<i>Therapist Factors</i>	9 (53%)	6 (60%)	15 (56%)
	<i>Face-to-face is helpful</i>	11 (65%)	7 (70%)	18 (67%)
	<i>Face-to-face is too much</i>	12 (71%)	4 (40%)	16 (59%)

EXPERIENCES OF GUIDED SELF-HELP

1.7 Screening and Measures	<i>Positive Aspects</i>	13 (76%)	7 (70%)	20 (74%)
	<i>Negative Aspects</i>	8 (47%)	7 (70%)	15 (56%)
Domain 2:				
2.1 Previous Support		9 (53%)	6 (60%)	15 (56%)
2.2 Expectations		6 (35%)	4 (40%)	10 (37%)
2.3 Small changes that were manageable and made a difference but it's hard work	<i>Small changes have a big impact</i>	7 (41%)	4 (40%)	11 (41%)
	<i>Making Changes</i>	10 (59%)	4 (40%)	14 (52%)
	<i>You've got to put the effort in</i>	11 (65%)	6 (60%)	17 (63%)
2.4 Outcomes for the whole family	<i>Impact on Child</i>	8 (47%)	10 (100%)	18 (67%)
	<i>Impact on Family</i>	10 (59%)	5 (50%)	15 (56%)
	<i>Impact on Parent</i>	14 (82%)	6 (60%)	20 (74%)
Domain 3:				
3.1 Tailoring	<i>Was tailored</i>	14 (82%)	5 (50%)	19 (70%)
	<i>Needs more tailoring</i>	4 (24%)	3 (30%)	7 (26%)
3.2 Understanding the neurological condition	<i>Understanding Epilepsy</i>	13 (76%)	9 (90%)	22 (81%)
	<i>Epilepsy made things difficult</i>	2 (12%)	3 (30%)	4 (15%)

Domain 1: The Good, the Bad and the Support

The first domain centred around participants' overall experiences of the intervention.

Participants talked about their experiences of the intervention as a whole, but also frequently mentioned specific techniques that they found helpful or unhelpful. Many discussed the importance of having guidance and a relationship with the therapist.

1.1. Overall Experience. The majority of participants reported a positive overall experience, both of the intervention itself and of the research study procedures.

"There was an enormous amount of benefit to be had from it." (P17)

"I'd definitely prefer this sort of intervention because its hands on, it's very practical and it's in direct response to what you're experiencing on a day to day level." (P15).

This was not universal, however; of the three participants who did not complete the therapy,

two reported that it was not helpful. One did not think that they learnt anything new, and the other felt it was not suitable for their child (a 15 year old with a primary presenting problem of anxiety).

“I didn’t feel anything different” (P1)

“Yeah we weren’t very impressed with it. Or it wasn’t suitable for [child].” (P7)

“It’s not helping a 15yr old get over her anxieties really.” (P7)

P7 seemed to associate the ineffectiveness of the intervention with the therapeutic relationship:

“I feel the counsellor should’ve maybe realised there wasn’t the rapport with [daughter] and herself.” (P7)

The remaining participant interviewed who had dropped out of the intervention did not relate negative experiences of the intervention. One said that they did not start the intervention after assessment because of the demands on the parents required:

“I think we were more involved in the therapy... so I thought it was too time consuming for us.” (P3).

1.2. Specific ideas. Participants often described one or two specific strategies or ideas as being key to the success of the intervention for them, but the specific strategy that was considered helpful varied amongst participants. For behaviour cases, the most commonly reported helpful strategy was ‘one to one’ or special time; six participants explicitly mentioned this as having been of benefit.

“Specific strategies that I had not thought of before, particularly the idea of having the one-to-one time.” (P8)

Whilst most participants reported similar strategies as being helpful they also reported being able to take away the strategies that suited them:

“Some worked really well, some didn’t.” (P9)

1.3. Practicalities. Patients appreciated the way that a telephone intervention was able to fit around their schedule and did not necessitate trips into the clinic, particularly as many lived a considerable distance away.

“I found the phone interviews fine, it didn’t take too much time up and I could carry on with my life after” (P4)

1.4. Stepped care. For the majority of families (n = 10), this brief telephone intervention was perceived as being sufficient for their needs. Although they recognised that there was still progress to be made, they felt that they had the strategies and techniques to maintain progress or cope with future difficulties; many commented that they periodically reviewed the self-help worksheets. For others (n = 5), although they found benefit from the intervention, they felt that more support was required.

“I think by the time we were finished, things were well on track.” (P4)

“I do feel we’ve now got the tools to deal with it.” (P12)

“I’d probably need more help myself with my anxieties about my child as well as about leaving her” (P2b)

The two follow-up calls were viewed as a positive way to reduce therapeutic input.

“That was good that there was something else towards the end of it. It wasn’t just sort of immediately stopping it, but more like a gradual withdrawal, which was easier.” (P19)

1.5. Better than doing it yourself. Whilst the convenient nature of telephone therapy was valued, participants overwhelmingly appreciated having guidance from the therapist. For some, simply having a space to talk openly was important.

“It’s such a positive feeling to have someone listening to you.” (P23)

Others commented on the benefits of having a therapist that can help talk through problems, discuss plans and bring new ideas.

“It was nice to just have someone to talk to about it and actually come up and brainstorm together.” (P25)

“If you were just left with a book the focus or motivation wouldn’t be there so much.”
(P14)

1.6. Importance of the therapist. For both parents and families, many reported that it was important to have a connection with the therapist. The initial face to face assessment was considered necessary by many, as it enabled them to build a relationship with the therapist and know who was on the other end of the phone during calls, *“so you know who you’re speaking to, you’re not just speaking to a stranger each week”* (P12).

“It is very important to have someone the child clicks with.” (P19)

“I found face to face helpful because firstly they met [child] so they could see what [child] was like but also I could tell them face to face some of the concerns I had and maybe go into a bit more detail than you could if it was a questionnaire or over the phone.” (P4)

However, following this first face to face assessment appointment, the practical nature of telephone therapy was preferred by most participants, with 16 directly stating this.

“Personally I like doing it over the telephone.” (P13)

1.7. Screening and measures. Most participants (n=19) reported positive experiences of the screening process.

“It was quite helpful because there was lots of different like options and everything which you can kind of relate to so it was good because you make yourself more aware of all the different kind of like problems and stuff which are linked together I guess.”
(P5a).

Three families reported negative experiences, for example due to the length of the questionnaire (n=1) and the results introducing new worries (n=1). Whilst one family reported that completing the questionnaire in clinic “*was good because [child] was sort of in an epilepsy mode so she wasn’t trying to pretend she was something else*” (P19), one family would have preferred to complete the questionnaires elsewhere.

“it would be nice to do it in a more private setting perhaps” (P23).

Domain 2: Surprises: Small Changes, Hard Work but Big Impact

The second domain focused on the expectations, process and outcomes of the intervention. Whilst many families entered the intervention with no or low expectations of the therapy considering its brief nature, the intervention surprised many. Relatively small changes were found to have far reaching impacts for not only the child themselves, but also their parents and wider family, as well as the school system. However, when families are under significant pressures already, such changes could be difficult to implement and maintain.

2.1. Previous support for mental health difficulties. Many had not had previous support (two participants stated that they had not known that support was available; 6, 18). Over half of the families had tried to access and/or received support previously and for those who had experienced previous interventions, none reported having found any of benefit:

“We tried a number of things and they hadn’t been particularly effective.” (P17)

“[Previous treatment] was just a general chat really about how she was feeling and it didn’t go beneath the surface at all and there were no practical things to do, you know, there were no sheets to follow up on, there was nothing, no structure to it and then it just stopped because the person who was doing it, left and that was the end of that, but I was quite happy for it to stop because I didn’t feel that it did any good at

all.” (P17)

For many, previous interventions had been considered unhelpful because of the lack of flexibility in their delivery.

“This one they seemed to want to work with you as to what you thought and guide you along that way whereas the previous meetings that we had it seemed to me at the time to be very set in stone, you do it this way, and that’s got to work.” (P10)

“I think because its, nationally, its one cap fits all, rather than actually, they like to put children into boxes I suppose.” (P12)

“All [a previous psychologist] was able to do was give me some print outs, without any guidance, she gave me some like print outs that I could’ve probably got off the internet about child’s behaviour where it just gives you little hints on things to do.” (P13)

2.2. Expectations. Perhaps because of previous experiences, many families reported low or no expectations for the intervention, yet were willing to have a go.

“I’m all for helping myself out so I was more than willing to participate and willing to try something new.” (P15)

“I wasn’t expecting it to be as structured as it was ultimately.” (P23)

2.3. Small changes that were manageable and made a difference but it is hard work. Contrary to expectations, whilst the intervention did not necessarily solve all problems, focus on the parents’ and/or child’s goals had a positive impact. This took work to achieve and to maintain.

“It’s certainly helped my daily life.” (P25)

“You’ve got to be prepared to put the effort in.” (P4)

2.4. Outcomes for the whole family. Many positive outcomes were noticed, which impacted on families' day to day lives. Participants who had a main goal related to ODD (and therefore who were most likely to have received a behavioural parenting intervention) were more likely to report outcomes for the parents and family, whereas those with a main goal related to anxiety/depression (and therefore to have received child focused CBT modules) were more likely to report outcomes for the child/young person.

"She definitely was brighter and happier and the neurologist noticed that." (P17)

"They made us think about different ways of approaching things." (P6)

"[Before the intervention] it wasn't working, me screaming like a demented banshee was not helping my child." (P15)

"Honestly it's changed our lives." (P12)

Domain 3: Knowing Me

The final domain covers the extent to which parents felt that the neurological condition was important in the therapy, and the extent to which the therapy suited their child's needs given that it was standard and not specifically adapted for people with neurological conditions.

3.1. Tailoring. Although the intervention was not explicitly tailored for the neurological condition in terms of the materials covered, which were standardised, parents reported that the intervention was tailored appropriately to their needs, through working through particularly goals, and to some extent choosing the particular strategies that they wanted to focus on.

"We felt that she really understood our child, what we wanted to achieve, where we were prepared to go and not prepared to go, what was really important to us, and then was just super flexible in terms of making it work for us." (P9)

3.2. Understanding the neurological condition. On the whole, parents felt that it was important that the therapist had some knowledge of the neurological condition. Whilst they did not expect the therapist to need in depth knowledge of the medical details, appreciation of both the emotional impact of having a neurological condition on the child and family, as well as more practical considerations regarding cognitive aspects, such as tiredness, ability to concentrate and levels of understanding, were important.

“Obviously they don’t need to know the ins and outs of epilepsy and the medical terms, but I think someone’s got to understand that having epilepsy must be like you’re walking on a frozen lake, waiting for it to crack.” (P2b)

The neurological condition also made the intervention more difficult at times, particularly as health states and medications varied. Parents felt that it was important that the therapist could understand and work with these issues.

“There were weeks when I thought this is really working well, this is brilliant and then he changes drugs and we go back to square one.” (P9)

Discussion

This study aimed to investigate the experiences of parents and young people of a brief, telephone guided self-help intervention for mental health disorders in the context of a chronic neurological condition. The overarching themes covered i) the experiences of the intervention ii) the outcomes of intervention and iii) the necessity of adaptations to account for chronic illness. These themes broadly correspond to the experiences of therapy that was i) remotely delivered by telephone (and the practicalities of this), ii) brief and yet had positive outcomes, and iii) not adapted for the neurological illness but was delivered by therapists with experience of the conditions. Overall, the results of this qualitative analysis suggest that this brief telephone delivered intervention was considered acceptable and suitable for many

families' needs, without the need for further adaptation.

Telephone delivery of therapy

The theme covering the experiences of therapy identified sub-themes regarding the positive aspects of telephone therapy, which were largely practical, in that it enabled families to fit the sessions around their lives more easily. This is consistent with previous qualitative studies of the experiences of delivering CBT to under-treated groups. For example, one study found that parents of rural Latino children with anxiety disorders expressed a preference for telephone delivered guided self-help due to 1) the inclusion of parents in the intervention, 2) a skills based focus, 3) greater comfort completing treatment in their own home and 4) the opportunity to learn skills and complete activities in their own time.³⁸ Similar themes of autonomy (comprising self-efficacy, flexibility and secure self-disclosure) and support (comprising clinician support, parental support and identification/normalisation) were found in a recent study of adolescents' experiences of internet-delivered cognitive behaviour therapy for obsessive compulsive disorder.³⁹ The presence of guidance was thought necessary; no patients expressed a preference for unguided self-help.

Brief therapy

Despite its brief nature (10 half-hour sessions, as opposed to around 12-16 hours of therapeutic contact in typical CBT interventions for children and adolescents⁴⁰), the vast majority of participants thought that they gained benefit from the intervention, although not all and for some different/more intensive support may be required. For many, the changes were significant and the families felt that the amount of input was sufficient. Despite the intervention being clinically 'low intensity' from the viewpoint of therapeutic input, it was perceived as being intense and hard work from the viewpoint of the parents and young

people. Participants who had a main goal related to ODD (and therefore who were most likely to have received parent focused intervention modules) were more likely to report outcomes for the parents and family, whereas those with a main goal related to anxiety/depression (and therefore who were likely to have received child focused CBT modules) were more likely to report outcomes for the child/young person.

Unadapted therapy

The question of whether or not evidence-based mental health therapies need to be adapted to account for chronic illness, with chronic illness specific content (such as psychoeducation about the illness) is important, as an unadapted therapy would be easier to roll out to generic Child and Adolescent Mental Health Services. Yet, whether and how much to adapt therapy has been little studied in children and young people with mental health conditions in the context of chronic illness. Almost all participants thought that it was important that the therapist had some knowledge of the neurological condition. They did not expect therapists to have full medical knowledge of the condition, however. Rather, they wanted the therapists to understand the day-to-day difficulties of having/being a child with epilepsy and often having associated cognitive difficulties. To date, only one other randomised controlled trial has investigated the efficacy of intervention for mental health disorders in the context of paediatric epilepsy and this intervention similarly only adapted the intervention to account for cognitive difficulties (including longer sessions and more concrete language) with positive results.⁶

Despite the intervention not being adapted for children with chronic illness specifically, and the wide range of cognitive abilities and additional comorbidities, most participants considered it adequately adapted for their/their child's needs and did not think that further adaptations were needed. This was largely because individualised goals were

chosen and participants were able to select and continue with the strategies that worked best for them. Interestingly, although participants considered that the intervention was appropriately tailored for their own needs, the majority of participants identified similar strategies as being helpful to them in Theme 1. This suggests that it is not necessarily flexibility in terms of the actual content of the intervention that is needed (and therefore that unadapted therapy is appropriate for their needs), but instead flexibility in the *delivery* and personalisation of the therapy to individual circumstances is required. For many, previous interventions had been considered unhelpful because of the lack of flexibility in their delivery. A qualitative investigation of the user perspectives on low intensity interventions for obsessive compulsive disorder found that ‘therapists were perceived to play a valuable role in personalising therapy’, by ‘outlining the relevance of therapy components to their problems and particular circumstances’ (p. 5).⁴¹

Limitations

The main limitation of this study is the selective sample. Almost all of the participants who chose to be interviewed were those that successfully completed the intervention and are therefore more likely to have gained benefit and/or found the intervention acceptable compared to those who dropped out. However, the majority of randomised participants did complete the intervention and we were successful in managing to interview 3 of the 7 participants who dropped out of therapy and their views were included in the full qualitative analysis. The majority of the missing data therefore relates to those who chose not to take part in the screening and/or intervention study at all and so research into the perceived barriers and facilitators of screening for mental health problems and guided self-help interventions for this group is needed. Similarly, there is likely to be a confound between efficacy of the intervention and subjective experience of the families in multiple domains,

including therapeutic alliance.⁴² In addition, those who chose to take part in the intervention were people who were experiencing difficulties but these either i) had not been identified previously or ii) had not been offered support suitable for their needs elsewhere. Further research to investigate the experiences of support from local Child and Adolescent Mental Health Services would be beneficial. As families were not randomised to receiving standard CAMHS support/face to face treatment, we do not know how the acceptability or efficacy of this intervention compares directly with those families who receive CAMHS support. We also did not interview participants following the period on the waiting list and so do not know the extent to which the outcomes presented are attributable to the specific intervention.

As a qualitative study, the results are partly constrained by the perspectives of interviewers and the study team. The interviewers were independent of the intervention, although were under the supervision of the intervention team and the analysis was completed by the study therapists.

Conclusions and avenues for further research

Overall, this research demonstrates that it may be possible to use an unadapted telephone delivered guided self-help intervention for mental health disorders in the context of neurological conditions, and that this is considered acceptable by many families. Parents completing these interviews did not think that the intervention needed specific content adaptations for children with neurological conditions. This may suggest that the intervention could be used across other chronic illnesses, however further research is needed to investigate its suitability for other populations. Importantly, given that some participants did not consent to or complete the screening process and/or intervention, and that few of these took part in this qualitative analysis study, further research is needed to understand the barriers to mental health screening and completion of a guided self-help intervention.

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