Cognitive-behavioural treatment of functional neurological symptoms (conversion disorder) in children and adolescents: A case series.

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Aim: To describe a cognitive-behavioural treatment and clinical outcomes in a series of children with functional neurological symptoms (FNS).

Method: Thirty-six children with FNS were assessed and of these twenty-two (13 male, 9 female) with a mean age 14.5 years (SD=2.6, range 6-17 years) completed treatment with cognitive behaviour therapy embedded in routine child and adolescent clinical/systemic practice. Treatment outcomes were measured at baseline and post-intervention on the Child Global Assessment Scale (CGAS), Strengths and Difficulties Questionnaire (SDQ), Goal Based Outcomes (GBO) and Revised Child Anxiety and Depression Scale (RCADS).

Results: Scores on the CGAS improved significantly post-intervention ($p<0.001$) with 82% of participants showing reliable change. Individualised goals (GBO) also showed clinically meaningful gains. Standard measures of emotional and behavioural symptoms (SDQ and RCADS) did not correlate well with clinical diagnoses, were usually subthreshold at baseline, and did not show significant improvement post-intervention.

Interpretation: The outcome of this pilot study suggests that CBT can be effective in the rehabilitation of young patients with FNS. Detection of common comorbid psychiatric disorders was not assisted by use of standardised measures, although most participants were clinically anxious or depressed. More research is needed to understand why children with FNS and their parents may not endorse mental health symptoms on questionnaires, and to further evaluate interventions within randomised controlled trials.

Keywords: functional neurological symptoms, conversion disorder, children, adolescents, treatment

Highlights

- **Cognitive-behavioural treatment for childhood functional neurological symptoms is described in a case series.**
- **The intervention results in improved functioning**
- **The majority of these children had clinical diagnoses of anxiety and/or depression**
- **Standard questionnaires do not detect anxiety/depression in this population.**

1. Introduction

Functional neurological symptoms (FNS) are a heterogeneous group of conditions characterised by presentations of altered neurological function or behavioural changes not explained by underlying neurological disease or injury.[1] FNS are classified as Functional Neurological Symptom Disorder (FNSD) or Conversion Disorder in DSM5.[2] Synonyms or related phenomena include 'somatoform', 'psychogenic' and 'medically unexplained neurological symptoms'. Common symptom presentations include non-epileptic seizures, sensory phenomena, motor phenomena, perceived cognitive problems (such as memory loss) and pain.[3]

Functional symptoms in children present a diagnostic challenge and are often resource intensive in the paediatric population.[4] There is a lack of data on the incidence, impact, associated factors and outcomes of FNS in children. One study, likely to be a low estimate, children reported an incidence of conversion disorder of 1.30/100 000 with the most common symptoms being motor weakness, abnormal movements and non-epileptic seizures.[5] Additionally this study indicated that outcome in terms of FNS symptoms at 12 month follow-up is generally good although in this study 28% of individuals were diagnosed with a new psychiatric disorder at follow-up. This suggests that in children with FNS, consideration of comorbid psychiatric conditions is important at assessment and for planning treatment.

FNS in the adult population is associated with self-reported disability and significant emotional distress and unemployment.[6] In the child population FNS are associated with significant emotional distress including symptoms of depression and anxiety.[7,8] FNS are also associated with detrimental impact on family functioning with decreased quality of life among parents of affected children[9] and increased parental anxiety, depression and somatization.[10] Children with FNS frequently have reduced school attendance and use health services more than control populations. Furthermore, FNS often remain undiagnosed and misunderstood and can lead to unnecessary and even harmful investigations.[11]

Despite the significant burden of FNS, there is a lack of intervention studies. Professionals often report uncertainty and unease in managing young people with the condition[12]condition Young people and family members emphasise the lack of understanding of FNS among professionals and young people report feeling isolated and stigmatised.[11] Psychological treatment is seen as key to successful intervention and outcome and there may be better outcomes for young people with FNS than adults.[8] Recent systematic reviews of treatments for other somatic symptom disorders indicate that cognitive-behavioural approaches have the strongest evidence for efficacy.[13] However, to date there have been few trials of treatment in FNS, other than for pain.[14] There have been some encouraging clinical outcome series including in pain[15], including a 2 year follow-up study in children with non-epileptic seizures.[16]

There is a need to develop and evaluate psychological interventions for FNS in the paediatric population. We describe a case series of young people who received psychological treatment as part of normal clinical practice. As a naturalistic study, this incorporates the heterogeneity seen in this population, including the collaboration needed with paediatricians regarding ongoing medical management of co-existing medical problems

such as epilepsy. The primary aim is to describe the outcome of a cognitive-behavioural intervention for children presenting with FNS. Additional mental health needs are also considered.

2. Method

2.1. Setting and participants

The patients in the case series represent sequential referrals for FNS seen for assessment and treatment by the Psychological Medicine Team at Great Ormond Street Hospital (GOSH) in London UK. Referrals are for young people aged up to 17 with FNS from both within GOSH and from paediatricians and psychiatrists around the UK. At referral the diagnosis of FNS has already been established. In all cases the diagnosis has been made clinically, following investigations as needed, by experienced paediatricians/paediatric neurologists.

In this case series, FNS are defined as neurological symptoms with no known medical cause, or where the degree of symptoms is much greater than would be expected from any known medical condition. Children who had a mixture of both medically explained neurological conditions (e.g. epilepsy) and FNS (e.g. non-epileptic seizures) are included. There was no requirement for children to have a separate mental health diagnosis in addition to FNS and children were not ruled out if they had other neurodevelopmental or cognitive difficulties.

Thirty-six patients aged between 6 and 17 years were seen for assessment between 2012 and 2017 and 33 were offered treatment within the Psychological Medicine Team. Of the 33, 27 took up the offer of treatment, whilst 6 either declined treatment or dropped out of treatment. By 2017, 22 had completed treatment, with 5 still being in treatment. The 22 patients who had completed treatment are included in the current study (Fig. 1). The characteristics of all participants are described in Table 1.

2.2. Assessment

Patients attended a multi-disciplinary diagnostic assessment, led by a consultant psychiatrist or consultant psychologist. Prior to the assessment all relevant medical and mental health reports were collated and summarised. The detailed half-day assessment included interviewing the parent/carer(s) and child/young person together, as well as individual interviews with both. Measures of psychological symptoms and impairment were those used as standard in the service at that time with additional measures chosen according to individual presentation. The measures used are in line with those recommended by the Child and Adolescent Mental Health Service (CAMHS) Outcome Research Consortium (CORC) (http://www.corc.uk.net/), a UK collaboration aiming to promote consistent outcome measurement in work with children and young people experiencing mental health difficulties.

2.2.1. Measures

Strengths and Difficulties Questionnaire (SDQ) (parent and self-report): The SDQ is an emotional and behavioural screening test designed to measure the following 5 areas: emotional symptoms, conduct problems, hyperactivity, peer relationship problems and prosocial behaviour.[17] The scores from four of the subscales are summed to give an overall total problems score (range 0-40, higher scores indicate greater difficulties). There is good

evidence of adequate internal consistency (test–retest reliability, predictive validity, discriminant validity and concurrent validity) to discriminate between clinical and nonclinical populations.[18]

Goal Based Outcomes (GBO): Goal based outcomes measure progress towards the particular improvement or goals a young person or their family have chosen to work on with Child and Adolescent Mental Health Services (CAMHS).[19] It represents a personalised measure of functional impairment, targeting change most relevant to the young person and their family. It is rated on a 0 to 10 scale (0 is not begun to achieve goal and 10 is really good/goal achieved, 5 is halfway). There is currently no data available on the reliability of GBOs but progress on goals correlates with symptom improvement, rated both by carers and clinicians.[20]

Children's Global Assessment Scale (CGAS): The CGAS is a global clinician rating used to assess young people's social, emotional and behavioural functioning from 0 (very poor functioning) to 100 (very high functioning).[21] The CGAS has been reported to have good concurrent and discriminative validity and reliability between raters[21] as well as adequate test-retest reliability.

Revised Child Anxiety and Depression Scale (RCADS) (parent and self-report): The RCADS is a 47-item self-report age-normed questionnaire, with scales corresponding to separation anxiety disorder (SAD), social phobia (SP), generalized anxiety disorder (GAD), panic disorder (PD), obsessive compulsive disorder (OCD), and major depressive disorder (MDD).[22] Items are scored 0–3 (corresponding to "never," "sometimes," "often," and "always"). The RCADS demonstrates sound psychometric properties including reliability,[23] predictive validity[24] and internal consistency.[25]

2.3. Intervention (see Table 2 for details)

Following assessment, each participant received individually tailored family-based cognitive behaviour therapy (CBT). This included individual treatment sessions with the child, parent management sessions, joint family sessions incorporating sessions on psychoeducation and seizure management and careful liaison with all relevant parts of the child's network including school. CBT is a widely used psychological treatment that aims to improve day-to-day functioning as well as physical and emotional wellbeing. In this context it was focussed on helping children and their families understand their physical symptoms, the causes of them, and learning how to change responses to them if necessary. On average, children received 12 sessions of CBT for their FNS.

Many children also had additional mental health conditions for which they also received evidence-based CBT treatment. For this reason, the number of treatment sessions varied between children. Sessions occurred on a weekly basis until the end of treatment. All sessions were conducted by one of four qualified clinical psychologists in the team. The CBT protocol incorporated standard CBT principles, and was largely delivered either in the presence of parents, or with parents joining for a summary at beginning and ends of sessions, as is common practice in CBT with children and adolescents. It has been shown

that involving parents in cognitive behavioural therapy, including helping to motivate the child and reinforce the new desired behaviours (with for example small rewards) improves outcomes.[26]

None of the patients received other forms of psychotherapeutic intervention. However throughout, there was emphasis on involving all other professionals involved in the child's care, the school and the family and other carers. If for example the child was also receiving physiotherapy, contact was made to ensure that all clinicians shared an understanding of the condition, and communicated as near as possible identically with the family. This was facilitated by – for example – ensuring that formulation and summary letters, with key management strategies were sent to the whole network. The stages of treatment are summarised in Fig. 2 and more details of CBT sessions in Table 2. Delivery of the intervention for each child was personalised so the sequence of sessions may have differed for each child. Reasons for this included significant low mood or issues around risk, which may have meant that CBT sessions for low mood were started first, followed later by seizure management sessions.

The initial phase of treatment consisted of psychoeducation on FNS for all children, their families and relevant members of their network. The aim of this psychoeducation was to increase children's and families' ability to incorporate environmental and psychological factors into the explanation of symptoms. This included ensuring an understanding that the physical symptoms were serious and would be the focus for intervention. Children and families were helped to understand the role of physical, psychological and environmental factors in a wide range of health conditions including FNS.

The second phase of treatment involved identifying maintaining factors and stressors in the occurrence of symptoms. Families and schools were encouraged not to respond to acute events as medical emergencies, but to adopt a calm approach with minimal disruption or attention. In parallel, children were encouraged to identify early-warning signs of FNS and to begin slowly and systematically re-introducing themselves back into situations they were avoiding. Homework was set for the child and family each week, with graded reduction in avoidance and functional rehabilitation. Close contact was maintained with schools and other key components of the child's network. Environmental stressors which were identified as potentially contributing to the FNS were addressed, for example putting support in place for previously unidentified specific learning difficulties, or addressing issues with bullying at school.

Finally, co-morbid mental health difficulties were treated with standard evidence-based treatments.[27] These mental health symptoms had often already been identified as stressors contributing to the FNS.

The case vignette below highlights the degree of flexibility and complexity that cases incorporated, but also the adherence to a graded exposure based cognitive behavioural model, with a focus on reducing avoidance, building resilience and understanding, and rehabilitation.

Case Vignette

Sam, a 16 year old boy, was referred with a year long history of episodes confirmed - following video telemetry - to be non-epileptic seizures (NES). These occurred primarily during the school day, but also at weekends and at home. In the year prior to the onset of NES his school attendance has been poor, with frequent absences due to abdominal pain and headaches.

Initial clinical assessment revealed a boy with long standing anxiety symptoms, currently meeting criteria for social anxiety, although he and the family felt that he disliked social environments because of worry about seizures. School attendance was very poor, and every time he had a seizure at school his parents were called or, if the episode was prolonged, an ambulance.

The family understood that epilepsy had been excluded, but found it worrying and puzzling how Sam could be having 'seizures'. They were willing to engage in treatment with the team.

Initial joint aims were established, which included reducing or eliminating NES and their impact and trying to understand why they were happening. Sam also said he would like to feel more confident with friends and be able to join a sports club.

The first phase of treatment included education about NES, with examples for the whole family about how physical symptoms can occur in surprising and disruptive ways and in the absence of serious underlying disease. Following this, the family understood that NES were not dangerous or life-threatening. They agreed to school liaison and, over the next 4 weeks, worked with the team and the school to change the responses to NES when they occurred in the classroom. With support, including a letter form the epilepsy clinical nurse specialist and paediatrician, the school agreed to stop calling ambulances for the typical episodes. Friends were encouraged not to make a fuss when Sam was experiencing an episode, and rather than trying to comfort him, when he 'came round' to join him for an activity.

At home the parents managed to stop shadowing Sam around the house, even though there was a scary moment when he had an NES near the top of the stairs and the parents feared he would fall. . Weekly telephone support for parents was provided to facilitate this and deal with anxieties as they arose.

The frequency and length of seizures began to decrease.

In parallel, a cognitive assessment had been carried out, which revealed that Sam had significant difficulties with literacy, despite overall being an above average student. Once this had been identified, the school allocated 10 minutes each day for a teacher to help Sam interpret written instructions. Sam's parents also arranged some specialist teaching for children with dyslexia. The school agreed to apply for extra time for exams.

Sam continued to be very anxious in social settings but insisted it was because he might be embarrassed by having an NES. Without challenging this directly at this stage, his therapy sessions now began to include an evidence-based social anxiety module. This incorporated graded therapist-assisted, in-session exposure, with walks outside the hospital, visits to shops and cafes, asking strangers for directions etc., all the time monitoring anxiety. As part of this Sam was encouraged to appraise his fear of having seizure and what potential reactions might be. In between sessions Sam

and his therapist devised behavioural experiments (exposure tasks) to practice each day at home and at school.

After 8 more weeks of sessions, and two telephone calls to the school to support management of NES if they occurred, Sam's NES had stopped. His social anxiety treatment was going well and he had joined a local judo club.

The remaining 2 sessions focussed on relapse prevention- discussing what the family had learnt about how Sam's body responds to stress and anxiety. There was a review of how he now had a better understanding of anxiety and its treatment, the importance of continuing challenge of avoidance, what might be future likely triggers and how to deal with them, and how much more confident he felt now he was getting regular support for dyslexia.

A one month and 3 month follow-up appointment were arranged.

2.4. Data Analysis

Descriptive statistics for total scores on each instrument before and after intervention are provided. Due to the small sample size and the heterogeneity of the data , results on the CGAS, total SDQ and total RCADS were first analyzed at the individual level by reliable change analysis, which determines whether the degree of change on each measure was statistically reliable, and not due to measurement-error[28]. This allows for classification of patients as either i) reliable deterioration, ii) no change or iii) reliable improvement. Where the majority of participants showed reliable change a group level analysis was then performed with total scores compared using Wilcoxon signed ranks test.

As there are no known studies investigating psychometric properties of GBOs we limited analysis of this data to a descriptive comparison of change in our series to benchmark data (the UK Increasing Access to Psychological Therapies program for children and young people - CYP IAPT - data set from 2011 to June 2015 which includes data from 75 separate services).[29]

All statistical analysis was carried out using SPSS version 23 (IBM SPSS Statistics, IBM Corporation, Armonk, NY).

2.5. Ethics

The project was registered with and approved by the Great Ormond Street Hospital Clinical Governance and Safety Department as a Service Evaluation.

3. Results

Twenty-two children underwent and completed treatment within the timescale of the study.

Thirteen of the participants were male and nine were female. Mean age at assessment was 14.5 years (SD 2.6). Four of the children had an illness duration of less than 1 year, nine 1-2 years and nine children 2 years or more. The most frequently occurring FNS subtype was

non-epileptic seizures (13) followed by motor symptoms (9). However, the participants often presented with symptoms in multiple domains with 15 having symptoms in at least two domains.

At initial clinical assessment 18/22 participants met criteria for at least one additional psychiatric diagnosis as well as FNS and 10/22 participants met criteria for two or more additional psychiatric diagnoses. However, SDQ Total Difficulties Scores showed only 2/22DS falling in the clinically impaired range; for the RCADS 4/16 participants had both parental and child measures in the clinical range for either anxiety or depression. 10/17 fell in the clinical range for depression on either parent or child report, but only in 3 cases did this correlate with a clinical diagnosis of depression. Overall where a clinical diagnosis was given only 9/18 cases had at least one corresponding high or clinical score on a relevant questionnaire.

Table 3 shows the mean scores of the psychological measures before and after intervention. Table 4 shows the goals chosen by participants clustered by the key areas to which they relate.

3.1. Individual Level Reliable Change Analysis

Eighteen of 22 participants showed reliable improvement on the CGAS; three showed no change and one showed reliable deterioration. Of the 15 participants who had both before and after parent SDQ data, 2 showed reliable improvement, two showed reliable deterioration and the remaining 11 showed no change on the total difficulties score. Of the 15 participants who had both before and after young person SDQ data, 3 showed reliable improvement, and the remaining 12 showed no reliable change on the total difficulties score. Of the 10 participants with before and after parents RCADS 2 showed reliable improvement on the total anxiety and depression score, 2 reliable deterioration and 6 no reliable change. Of the 13 with before and after child RCADS, 6 showed reliable improvement, 1 reliable deterioration and 7 no reliable change.

Thirteen participants had GBO scores both pre- and post-intervention. The mean GBO at the start of treatment was 2.78 (SD 1.69) and had risen to 7.79 (SD 1.90) by the end of treatment, giving a mean increase in goal ratings of 5.01 (SD 2.04). This compares to a mean increase in goal ratings of 3.7 for the entire CYP-IAPT 2011-2015 data set.

3.2. Group Analysis

The CGAS score increased significantly (43 to 66 – see Table 2 for details) from pre to post intervention ($p<0.001$) indicating significantly improved functioning.

4. Discussion

This is one of the first studies to describe a cognitive-behavioural intervention for children presenting with functional neurological symptoms (FNS). The resulting significant improvement in function provides preliminary evidence that these children respond positively to a cognitive behavioural intervention. As described, the therapeutic approach closely involved family and school, and was individually tailored to the needs of the child. The key approach – promoting change through psychoeducation, behavioural experiments (with in-session and between-session practice) and cognitive shifts, followed by relapse

prevention – represents a cognitive behavioural framework. Traditional mental health rating scales were not helpful in this population, as both children and parents did not endorse emotional symptoms on questionnaires, despite clinical evidence of anxiety and depression. This confirms other indications that conventional measures of emotional and behavioural symptoms, such as the SDQ, lack validity in this population.[30]

At assessment, CGAS scores ranged from 25 to 65 indicating that all had a significant degree of global impairment, including, at the lower end of the range, patients severely affected by their symptoms. Despite this and the heterogeneous nature of FNS in the sample, the majority showed reliable improvement on the CGAS and on achieving their treatment goals (measured by GBOs) suggests that a cognitive behavioural intervention for FNS may help children and young people to return to day to day life activities. There is limited research on the daily impairment experienced by children with FNS but in adults there is evidence that FNS are associated with self-reported disability and significant emotional distress and unemployment[31] highlighting the need for, and likely benefits of successful early treatment. It needs to be established whether treatment in childhood can reduce or alleviate the burden of the FNS and associated disability later in life.

High rates of comorbid psychiatric disorders have been reported in similar series of children with functional neurological symptoms, such as non-epileptic seizures.[32] Despite 86% of participants meeting clinical criteria for at least one mental health disorder, this was rarely picked up by questionnaire-based instruments that have been shown to have good reliability and specificity in other populations. One explanation for this discrepancy could be that children presenting with FNS may be less aware of such symptoms or experience them differently from those who have such diagnoses but do not have FNS. There is evidence of an association between FNS and alexithymia in the adult population.[33] There is however, mixed evidence of the association between FNS and alexithymia in children with some studies supporting the association[34] whereas others suggest that children with physical symptoms have difficulty in communicating negative internal states rather than difficulty in identifying emotions.[35]

A second possibility is that participants and their families might under-report psychological distress for fear that their difficulties will be seen as “all in their head” and thereby reduce access to potential medical treatment. Families certainly report such fears[12] and the communication of the FNS diagnosis in an empathetic manner has been identified as crucial with respect to outcome.[36] A third possibility is that the clinical psychiatric diagnoses might be incorrect, but these were made by experienced clinicians and the rates of occurring mental health diagnoses in this study are in keeping with other studies.[8] The lack of significant change on the SDQ and RCADS, measures specifically designed to capture mental health symptoms through self and parental report, is perhaps not surprising given the lack of endorsement and low rates of symptoms at initial assessment.

4.1. Clinical implications and future research

FNS in children are often under-diagnosed and consequently under-treated. The results of this study indicate that children and their parents should be offered a cognitive-behavioural intervention. The intervention used here was pragmatically driven by the individual child and family’s needs, but broadly based on cognitive behavioural principles. The components

of such a package could be more carefully defined and evaluated; for example in adults there is emerging evidence for the benefits of making a positive diagnosis of FNS, and providing clear and non-judgmental education and access to resources.[37,38] One small study in young people showed that giving a careful biopsychosocial explanation for (in this case) non-epileptic seizures, which incorporated an emphasis on the physical symptoms, and on 'believing' the patient, had beneficial effects.[39]

There is a need to consider how to assess the frequently occurring mental health symptoms before and after treatment in this population given the possible lack of validity of self and parental rating scales. It may be that these scales should not be used, and it would be better to rely on expert clinical diagnosis.

In the adult population with FNS there is increasing evidence that specific physical rehabilitation and psychological interventions alone or in combination can be beneficial although clinical trial evidence remains limited.[40] It will be useful to explore these approaches in children with FNS. Our preliminary case experience appears to confirm that a primary focus on the impact of the physical symptoms and their rehabilitation is crucial, although following engagement of the family the incorporation of CBT seems to offer opportunities to address a range of underlying issues, which might prevent a re-emergence of the same or new symptoms in the future.

Future needs include:

- Manualisation of cognitive behavioural protocols for paediatric FNS
- Randomised controlled trials to further evaluate the efficacy of cognitive-behavioural interventions;
- Determination of appropriate measures to assess comorbid mental health conditions in children with FNS;
- The development of validated measures of the symptoms, severity and impact of FNS in order to better assess treatment outcomes.

4.2. Limitations

The main limitation of this study is that there is no comparison group and so we cannot ascertain that any changes were due to the specific intervention rather than factors relating to the assessment or general therapeutic contact. This is a naturalistic sample arising from the daily clinical practice of the service, and represents a case series. Twenty-seven patients of the thirty three assessed with FNS in this period came into treatment with the team: the 22 included in this case series and five who are still in treatment. There is a lack of information about the outcomes in the six children who did not proceed with treatment and the five whose treatment is incomplete.

The criteria used to select patients for this treatment study were pragmatic, but include: the diagnosis being made definitively; families receiving and accepting onward psychological referral; families living near enough the hospital to attend for treatment regularly. So the sample reported here is selected from the many patients attending this specialist children's hospital each year. Previous audits and published papers from this specialist hospital suggest that about 20% of elective admissions are for medically unexplained symptoms, but

this diagnosis is not consistently named or coded, so the numbers are unknown. Previous prevalence studies in the hospital have suggested approximately 80 children with functional neurological symptoms were seen in a 2 year period.[41] This poor classification and data collection, as well as poor knowledge in paediatricians regarding onward referral for psychological treatment, has been recognised as a barrier to current detection and effective management of functional symptoms in children.[42]

Due to changes in clinical practice over the course of time, not all participants completed the same measures with the CGAS being the only measure which all participants had at both start and end of treatment. The CGAS was scored by treating clinicians and it would be better in future studies if raters of CGAS were independent and unaware of the treatment status. The data generated from this study can be considered case series pilot data and moving forward it is hoped to develop a treatment manual to ensure fidelity whilst at the same time recognising the need for flexibility in this group.

There was no specific measure of FNS included within the case-series. Whilst a number of questionnaire measures exist,[43] these are symptom checklists and include both medically explained and medically unexplained symptoms. These inadequacies with existing questionnaire measures, together with the wide range of symptoms reported in this case-series meant that no such measure was suitable.

5. Conclusions

The results of this study show that improvements in functioning for children with FNS are achievable using a cognitive-behavioural intervention involving affected child and parents. There is a need to manualise the treatment protocol and for larger randomised controlled trials of this intervention. Additionally there is a need for further research to better understand the assessment and subsequent response to treatment of the frequent mental health conditions in this population.

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Fig. 1: Recruitment of children with FNS

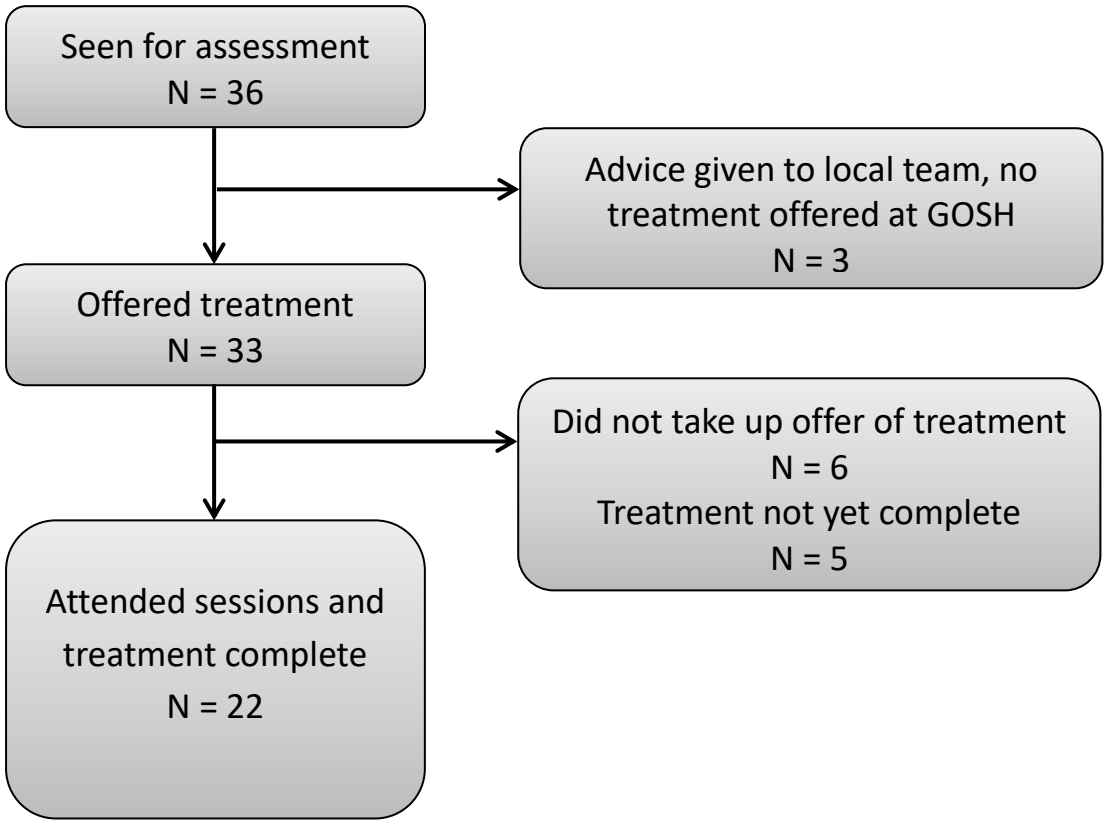
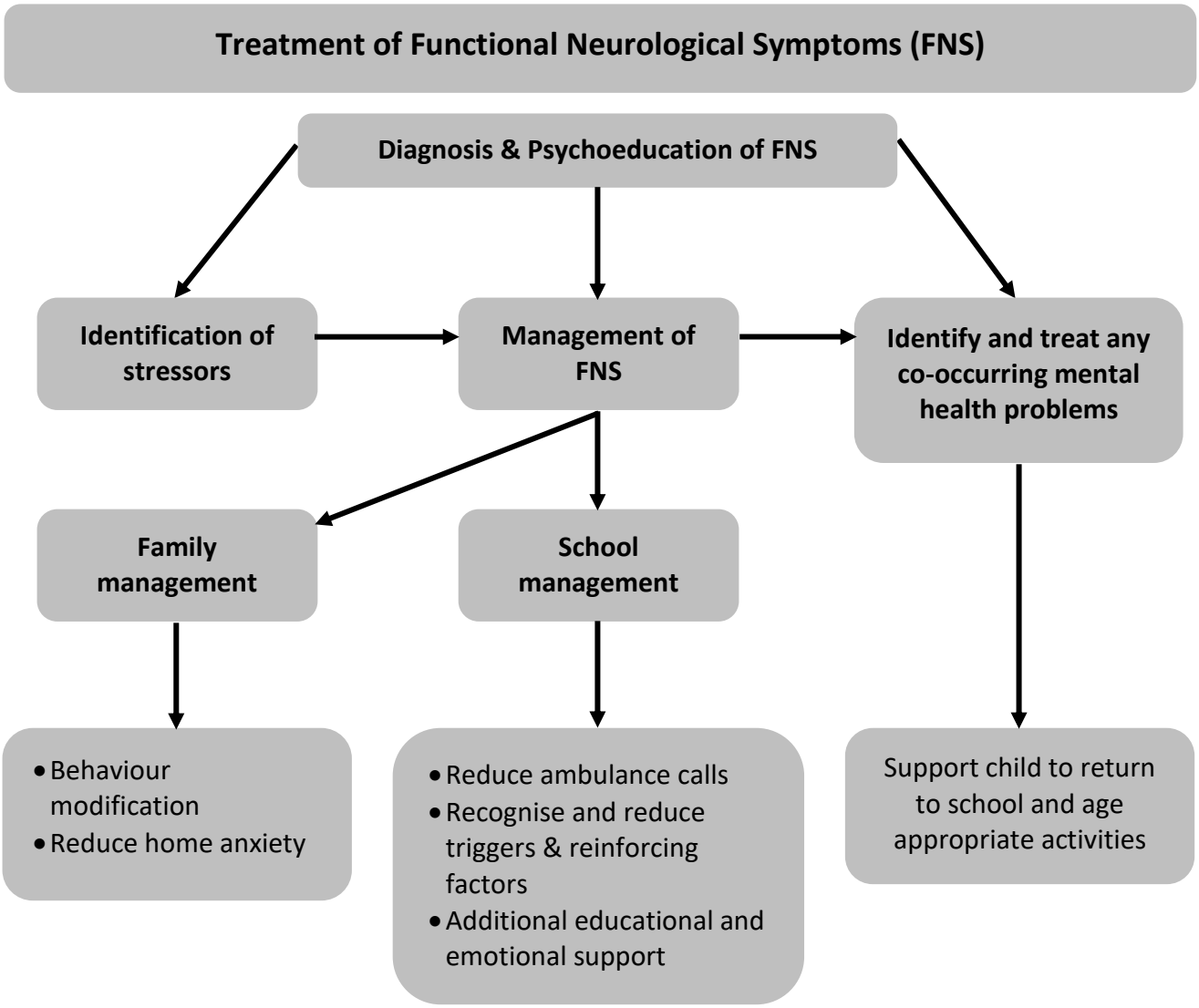


Fig. 2: Management of Functional Neurological Symptoms*



*Children may require all or only some of the elements above depending on clincial need.

Table 1: Characteristics of the children and young people with Functional Neurological Symptoms (FNS)

Patient	Gender	Age at Assessment (Years/Months)	Duration of illness	FNS symptoms				Mental Health Diagnosis
				NES	Motor (including weakness, paralysis, collapses)	Sensory (including pain, tingling, itching)	Other*	
1	Male	15:01	>2 years					-
2	Male	16:06	6-12 months	✓				Depression
3	Female	06:04	>2 years	✓				-
4	Female	15:05	1-2 years	✓	✓	✓		Autism, Social Anxiety, Tourette Syndrome
5	Male	15:11	1-2 years	✓	✓			Social Anxiety
6	Male	08:11	1-2 years	✓				Oppositional Defiant Disorder
7	Female	15:06	1-2 years	✓			✓	Depression
8	Male	12:10	1-2 years					Generalised Anxiety Disorder
9	Female	14:04	less than 6 months	✓	✓			Anxiety, Panic Disorder
10	Male	16:10	>2 years		✓	✓		Social Anxiety
11	Female	14:10	>2 years	✓	✓			Depression, Generalised Anxiety Disorder
12	Male	15:09	6-12 months		✓		✓	Depression, Social Anxiety
13	Female	14:09	1-2 years		✓			Depression, Generalised Anxiety Disorder
14	Male	12:07	>2 years	✓			✓	Tourette Syndrome, Generalised Anxiety Disorder, OCD
15	Female	15:02	6-12 months	✓				Generalised Anxiety Disorder
16	Male	14:01	>2 years			✓	✓	Autism, ADHD, Social Anxiety
17	Female	13:08	1-2 years		✓			Depression
18	Female	16:03	>2 years		✓	✓		Social Anxiety, Generalised Anxiety Disorder
19	Female	15:06	>2 years	✓		✓		Generalised Anxiety Disorder
20	Female	16:09	1-2 years	✓	✓		✓	Generalised Anxiety Disorder, Depression
21	Female	17:02	>2 years		✓			-
22	Female	14:01	1-2 years	✓			✓	-

*****nodding off to sleep, difficulty recognising faces, headaches, cognitive difficulties

Table 2: Details of the cognitive behavioural intervention for FNS

Session	Key strategies	Additional strategies for:		
		Child and parents	**Clinicians**	**School**
Sessions 1–2 Education	• Establish rapport; provide validation and reassurance • Review problem list; identify areas of most distress • Provide psychoeducation about FNS and treatment • Provide general outline for therapy process • Support patient to set goals for therapy • Emphasize importance of self-monitoring and at-home practice • Elicit reactions to sessions	• Discuss diagnosis of FNS and opportunity for questions •Understand the link between emotions and the body • Help to alleviate anxiety around medical cause • Build hope for the future • Importance of everyone working together	• Speak with the child's network • Create a shared understanding of the diagnosis and treatment plan • Discuss the potentially adverse impact of continued medical investigation, which then is not indicated on progress	• Help school staff to better understand the condition • To better understand the link between the body and mind • Engage them in the process of rehabilitation for the child • Opportunity for problem-solving day-to-day difficulties that may arise
Sessions 3–5 Identify stressors	• Provide relaxation training • Develop a hierarchy • Begin exposure and response prevention / activity scheduling • Address any issues related to not completing home assignments	• Work socratically with the child to explore what makes symptoms better or worse • Enquire about potential triggers preceding symptom onset • Support child to begin thinking of ways to problem solve their worries • Assist parents in identifying stressors contributing to the child's symptoms	• Consider the impact possible cognitive difficulties and/or other neurodevelopmental difficulties might be placing on the child	• Help school to identify stressors • Enquire and hypothesise with staff the impact of stress on the child

Sessions 6–8 Symptom control and behaviour management	• Review homework (i.e., relaxation techniques, thought–mood tracking, exposure tasks etc.) • Teach strategies for problem solving • Continue practicing exposure response prevention • Identify thoughts and challenge unhelpful thoughts	• Help child identify physical precipitants of the symptoms • Develop ways the child can improve symptom control • Ensure child is on board with school management plan to prevent further distress • Reflect on the reinforcing nature of positive attention towards symptoms • Support parents to provide positive attention and encouragement when the child is working towards increased adaptive functioning, and reduce time spent attending to or speaking about medically unexplained symptoms	• Discuss management of symptoms across the child's network • Discuss role of unconscious learning • Build motivation where there is ambivalence and/or resistance to treatment with the network	• Help school to weigh up risks and benefits of management plan • Develop a consistent way of responding to symptoms with the school • Invite school to reflect on any current unhelpful management approaches and discuss useful alternatives • Support school to provide positive attention and encouragement when the child is well so as to avoid reinforcing symptom maintenance
Sessions 9–16 Reestablishment of Regular Life Routines	• Review homework (i.e., relaxation techniques worry time, problem-solving) • Address issues related to not completing home assignments • Continue exposure tasks and thought challenging • Teach assertiveness and communication skills • Role-play with patient and assign homework to practice in real life • Elicit reactions to sessions • Discuss how to increase pleasant activity scheduling • Discuss mindfulness and acceptance of uncontrollable events	• Support the child to return to school using a graded approach • Help the child to think about how they will manage the reactions of peers • Support parents to return to their previous work schedules and daily routines • Help parents to encourage their child to return to school using a graded approach • If required, support parents through early period of increasing symptoms following implementation of the management plan	• Remote support for child's network via phone or email to support any difficulties that may arise • Keep child's network up to date with progress and or difficulties that arise • Start preparing any transition arrangements that might be in place to move child from specialist CAMHS (Tier 4) support to local CAMHS (Tier 3) support	• Help school to understand the factors that may hinder reintegration • Provide accommodations needed for learning, social, or other problems • Support schools with allowing the child to do more activities independently • Help the school to manage reactions of peers • Remote support for child's school via phone or email to support any difficulties that may arise

Session 17-20 Review, relapse prevention and termination of sessions	• Discuss importance of using all skills learned thus far to manage symptoms • Move toward termination • Review all skills–techniques–strategies learned to date • Discuss progress made in therapy, areas of continued effort, ongoing challenges • Elicit reaction to therapy process • Final session—termination	• Provide support to parents to problem solve any areas of difficulty. • Build awareness that new symptoms may arise but support child and parents to feel empowered in managing them • Support parents to develop consist way of responding with wider members of the family • Encourage parents to support child's problem and deal with worries when they arise to prevent relapse	• Inform the child's network of the progress made and plans for discharge • Disseminate summary of treatment along with recommendations for ongoing support for the child if needed	• Support school in maintaining level of support for the child in school • Build awareness that new symptoms may arise in school, but support teachers to feel empowered in dealing with them by reminding them of strategies already used with the child

Table 3: Scores on measures of psychological functioning for children with FNS before and after treatment

Measure	Pre		Post	
	Mean	**SD**	**Mean**	**SD**
GBO (n=14)	2.78	1.69	7.79	1.90
CGAS (n=20)	42.95	7.78	65.55	11.60
RCADS - Parent depression (n=10)	68.60	10.12	60.00	13.99
RCADS - Parent anxiety (n=10)	57.40	14.49	55.20	16.70
RCADS – Parent Total	60.90	4.02	56.30	5.20
RCADS – Child depression (n=13)	58.80	17.82	60.00	5.63
RCADS – Child anxiety (n=13)	50.77	18.24	45.38	11.80
RCADS – Child total (n=13)	52.31	18.58	45.62	12.07
SDQ - Parent (n=10)	13.06	8.46	12.31	8.36
SDQ - Self (n=15)	14.33	7.69	12.13	6.70

GBO= Goal Based Outcomes, CGAS= Children's Global Assessment Scale, RCADS= Revised Child Anxiety and Depression Scale, SDQ= Strengths and Difficulties Questionnaire

Table 4: Examples of goals chosen by children and families as target for CBT intervention

To acquire tools/strategies: • Improve problem solving skills in situations • Find and practice ways of sharing my emotions with others • Make a clear plan for how everyone responds to severe headache or collapsing • To have tools to help cope with the headaches (nausea), etc. • To find out my strengths and weaknesses and strategies that may be useful. • Express and manage emotions particularly anxiety • Have a plan of how to manage them	**Reduction in symptoms:** • To reduce the NES and for them to be less intrusive and get in the way of life less • Stop seizures • Not needing wheelchair • Resume walking • Free of absent episodes • To have fewer severe episodes • Understand feeling and to go away • Feel less tired day to day • Control mood swings • Headaches to be less debilitating • Be able to walk again • Be able to control tics • To reduce seizures at home • Reduce movements particularly in public • Episodes to stop	**Increase in confidence:** • To have more confidence when talking to other people • Start staying at home on own • See people more • Feel less anxious be happier and more determination to do things • Feel more comfortable around people • Do more things with friends • Speak more with people my age and adults and feel confident doing so • Feel more confident/happy in self • To be more independent • Be more confident talking to people and go to more social situations
Return to activities: • Return to horse-riding, swimming and join drama group • Start working out again • Be able to draw and write more • To return to activities	**Progress with school:** • To be able to be in school for all taught lessons • Return to school resume normal education • Normal life at home and school • Get to attend school • Finding out why not doing well in exams and coursework • Balance school work and life and not set self unrealistic expectations • To reduce seizures at school	**Increase understanding:** • Understand what triggers pain and how to cope • Understand how anxiety related to dizziness temper and sadness • Understand the episodes more • Be less worried about bad things happening