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Functional neurological symptoms: Optimising efficacy of inpatient treatment and preparation for change using the Queen Square Guided Self-Help

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Abstract

Objective: Functional neurological symptoms (FNS) are disabling symptoms without macro-structural cause. While inpatient treatment confers important benefits, it is resource-intensive, and hence, it is important to optimise its efficiency.

Methods: We developed a brief, Internet-based preparatory therapy based on psychoeducation and CBT, termed the Queen Square Guided Self-help (QGSH), to maximise the efficacy of the inpatient FNS treatment at the National Hospital for Neurology and Neurosurgery.

Results: The QGSH aims to ensure that prior to admission, the patient understands (a) the diagnosis of FNS, (b) the five-areas CBT model and (c) the use of goal setting in rehabilitation. It has now run since 2017, and 191 patients have taken part in the inpatient FNS programme, with 122 of these having participated in the QGSH. It runs for up to 12 weeks and includes original videos and patient worksheets, as well as signposting to existing published resources. Information is sent weekly by email, and content is delivered in the form of 11 modules built around online video sessions.

Conclusion: We believe that the set of materials used in QGSH has the potential to benefit patients with FNS and can support clinicians wishing to develop their expertise. It could help with the development of new FNS services, and we are in the process of developing it into a stand-alone service. We hope that the experience of the Queen Square team can be used to help patients and clinicians to improve the provision of FNS services.

KEYWORDS

cognitive behavioural therapy, functional neurological symptoms, guided self-help, rehabilitation

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1 | BACKGROUND

Functional neurological symptoms (FNS) are disabling symptoms without macro-structural cause (American Psychiatric Association, 2013). Previously, these symptoms have been described using a range of terms including 'hysterical', 'conversion' and 'somatisation', each with implications about the underlying mechanism. The variety of terms has left patients 'muddled' and can be seen as offensive (Stone et al., 2002). 'Functional' is now preferred as it is acceptable to patients and does not assume an underlying mechanism (Ding & Kanaan, 2016).

The diagnosis is based on a pattern of positive signs and symptoms that are characteristic of functional disease and that vary with time or attention (Carson et al., 2016). This is reflected in the DSM-5 and ICD-10 criteria (see Appendix 2). FNS may include motor symptoms, sensory disturbance or other neurological symptoms such as aphonia. An important subtype of FNS is non-epileptic attack disorder (NEADs), also known as dissociative or psychogenic seizures, which present with episodes of disrupted consciousness without EEG evidence of epileptic brain activity (American Psychiatric Association, 2013).

Functional neurological symptoms (FNS) cause a similar level of disability to 'organic' neurological disorders but with a higher rate of psychiatric comorbidity (Sojka et al., 2018). FNS is thought to account for between 6% and 16% of all neurology clinic referrals (Stone et al., 2010) with an incidence of 4–12 per 100,000 (Carson et al., 2012). 'Functional overlay', where functional symptoms coexist with 'organic' illnesses, is thought to occur in up to 30% of neurology patients (Stone et al., 2010), and it is thought that 10%–50% of patients with epilepsy may have a combination of epileptic and non-epileptic seizures (Gates, 2002). We place 'organic' in quotes to emphasise that all disorders of brain function have an organic substrate at the microscopic level of synaptic connectivity and neurotransmitter function. Similarly, we avoid referring to FNS as having 'no structural cause', preferring to talk about 'no macro-structural cause' as might be detected by current medical imaging.

The term 'organic' is commonly used to refer to disorders with well-established histopathological or neurochemical substrate, but its simplistic application in the case of FNS has caused many misunderstandings that the programme described in this article often has to address. Importantly, psychological factors and negative life events are thought to be part of a process of symptom emergence, contributing to disrupted attentional and emotional processing to produce and maintain symptoms (Pick et al., 2019). Yet, the role of psychological factors is controversial, as many perceive clinical formulations at the psychological or psychiatric level as discounting true distress, disbelieving or stigmatising sufferers as 'mad' and denying the role of the brain—while of course, they simply refer to a different level of brain function and structure, that of information processing and learning.

Regarding the place of information and learning in treatment, there is significant evidence that the quality of diagnostic explanation impacts the efficacy of treatment (Edwards, 2016) and a substantial minority of patients are symptom-free after the initial consultation alone (McKenzie et al., 2010). Additionally, patients feeling they are believed by their doctor is an important factor in their recovery (Karterud et al., 2015). Patient acceptance of the diagnosis, acknowledgement that emotion may play an important role in symptom production and a stable social environment all increase the chance of a good recovery (Reuber et al., 2005; Rommelfanger et al., 2017). On the other hand, poor outcomes are associated with expectation of non-recovery, non-attribution of symptoms to psychological factors and receipt of health-related benefits (Sharpe et al., 2010). Psychiatric comorbidity, particularly personality disorder, is also an important negative predictive factor (Gelauff et al., 2014). This may reflect the difficulty of treatment in the presence of another disorder, and in personality disorders, difficulties with collaboration with treatment.

Implications for practice and policy

- The QGSH has the potential to provide significant benefit for patients with FNS
- Therapy can be delivered remotely
- Clinicians can benefit from the materials and supportive structure
- QGSH could be introduced into stepped care for patients with FNS

1.1 | The multidisciplinary approach to inpatient treatment

Evidence supports both psychological and physical interventions (Conwill et al., 2014; Demartini et al., 2014; Sharpe et al., 2011), helping to overcome the difficulties from diagnosis to effective treatment that have historically troubled the management of FNS (Greiner et al., 2016). Acceptance of this multidisciplinary approach is illustrated by 55% of neurologists and 88% of psychiatrists favouring a combined treatment in one study (Schipper et al., 2014). Using a multidisciplinary team (MDT) of health professionals from a range of backgrounds can maximise the impact of each form of therapy by working co-operatively (Demartini et al., 2014; Hubschmid et al., 2015; Jordbru et al., 2014; Saifee et al., 2012). The National Hospital for Neurology and Neurosurgery (NHNN) offers a tertiary care, multidisciplinary treatment package for FNS, whose centrepiece is the inpatient programme.

1.2 | The need for guided self-help

While inpatient MDT treatment confers important benefits (Demartini et al., 2014), it is resource-intensive and hence under pressure to minimise its length. The shortening of admissions in

NHNN meant that many patients spent a significant proportion of their admission gaining an understanding of the diagnosis and the rehabilitative approach. Many expected an admission based on 'organic' investigations and medical intervention and had doubts about the biopsychosocial, goal-driven approach and how important self-management would be for effective rehabilitation. By the time a collaborative understanding of FNS has been achieved, there was often little time left for hands-on rehabilitation. Thus, we aimed to develop a preparatory therapy, termed the 'Queen Square Guided Self-help' (QGSH), based on psychoeducation and CBT, and to institute it as a key part of the treatment package so that patients would make the best use of the inpatient treatment.

2 | METHODS

We developed the QGSH through (a) considering the multidisciplinary approach that patients needed to learn about, (b) adapting existing guided self-help approaches, (c) incorporating an ongoing process of service evaluation and, finally, (d) aiming to provide the resources we developed to the community.

2.1 | Key therapies within the MDT

Our programme comprises the following physical, psychological, occupational, psychiatric and whole-team contributions.

Specialist physiotherapy for motor FNS, which focuses on retraining abnormal movements (Nielsen, 2016), can be highly effective (Nielsen et al., 2013). Significant improvements in physical function and quality of life sustained over follow-up have been seen (Jordbru et al., 2014; Nielsen et al., 2015).

Psychologically, we use cognitive behavioural therapy (CBT) for FNS (Dallocchio et al., 2016) within a broad biopsychosocial approach. The cognitive component aims to modify the patient's unhelpful beliefs in relation to their illness (O'Neal & Baslet, 2018). CBT has been found to be effective in studies looking at both one-to-one settings (Sharpe et al., 2011) and groups (Conwill et al., 2014). A range of psychological therapies have been used for FNS, including brief psychodynamic interpersonal therapy (BPIP; Sattel et al., 2012).

In QGSH, collaborative work in the therapy relationship is crucially informed by a psychodynamic 'lens'. That is, we think about the feelings of both patients and therapists during the work and how they may depend on past experiences, and discuss these in clinical supervision. This is 'lens' rather than 'technique', in that we do not use psychoanalytic interventions such as interpretations.

Occupational therapy for FNS is primarily concerned with function rather than impairment. An in-depth history taken from the individual allows the therapist to place them in the context of their wider biopsychosocial environment. Understanding a person's narrative is essential in planning rehabilitation and recovery (Nicholson et al., 2020). The nursing team also provide the detailed knowledge of a person's presentation throughout the day, which allows for a 24-hr dynamic risk assessment and so supports a therapeutic rehabilitative environment.

Expert psychiatric understanding is also important. Many of the more disabled FNS patients present with a range of functional symptoms in the presence of comorbid 'organic' diseases. A significant proportion present with psychiatric comorbidity and complex biopsychosocial presentations.

2.2 | The development of guided self-help

Self-help approaches have been established for many decades in the psychological therapies (2001, 2001).

These include, for example, bibliotherapy, where patients read recommended books and forms of computerised CBT delivered by CD or DVD or via the Internet. 'Book prescription' schemes where patients can borrow on extended loan specific books via a 'prescription' from a health professional is one way of making bibliotherapy more accessible. In advocating greater accessibility and flexibility in modes of therapy delivery, Lovell and Richard (2000) advocated for Multiple Access Points and Levels of Entry to therapy (MAPLE; Lovell & Richards, 2000). Thus, as well as part of an integrated care package, guided self-help may form one stage in a stepped-care programme. Indeed, NHS Scotland has advocated 'stepped care' for patients with FNS. Step 1 is diagnosis; Step 2 is a brief intervention; and Step 3 is complex care with a multidisciplinary team (Healthcare Improvement Scotland, 2012).

Cuijpers and Schuurmans reviewed the history of self-help interventions for anxiety disorders and outlined the forms it can take (see Table 1). The only RCT to investigate the efficacy of guided self-help for FNS was performed by Sharpe et al., providing class III evidence. Participants allocated to the UC + GSH condition showed greater improvement in the CGI with an odds ratio of 2.36 (95% CI: 1.17–4.74, p =.016). There was a 13% absolute improvement in the proportion rating their health as 'better' or 'much better', translating to

TABLE 1 Types of self-help summarised from Cuijpers and Schuurmans (2007)

Unguided self-help: Provided by a book or electronically via the Internet or computer programmes. There is no professional support of either the user's understanding of the method or how far to pursue it
Self-help as part of face-to-face therapy: Here, it can be used as part of regular treatment with a professional providing the patient with self-help materials to speed up the treatment process or to give them an opportunity to practise components of the therapy independently. For example, self-help sleep-hygiene guides are commonly used in the standard CBT
Self-help as an independent intervention: The patient works through a self-help workbook or worksheet with support from a professional at regular times. These are usually brief contacts aimed to provide added explanation about the methods where needed rather than developing a traditional patient–therapist relationship. The capacity for this has expanded significantly with the development of the Internet

a number needed to treat of 8. Much of the recent work on GSH has moved to Internet-based approaches, which can amplify the power of GSH.

In this light, the QGSH was developed as a brief therapeutic intervention, which aims to ensure that, prior to admission, the patient understands (a) the diagnosis of FNS and how their own diagnosis has been reached; (b) the five-areas CBT model and has started practising it and (c) the use of goal setting in rehabilitation. The 'five-areas' approach (Williams et al., 2011) consists of (a) Symptoms, (b) Cognitions/thinking, (c) Feelings, (d) Behaviour and (e) Life situation, and focuses on psychoeducation, explains FNS within a biopsychosocial model and teaches goal-oriented self-management to support engagement with the inpatient programme. The most important aim, however, is to develop a collaborative, trusting alliance with the neuropsychiatry multidisciplinary team.

2.3 | Service evaluation

In order to improve the QGSH, we developed an ongoing evaluation system based on a Patient-provided Routine Outcome Measure (PROM) and a complementary Clinician-provided Routine Outcome Measure (CROM). Both of these were produced in four stages: assembling items, preliminary scale evaluation, analysis of reliability and validity, and final clinical evaluation, in line with standard development of psychometric scales.

3 | RESULTS

Patients are referred to the overall FNS service by neurologists and neuropsychiatrists who have established the diagnosis and are first seen in a neuropsychiatry MDT clinic to assess their suitability for treatment. This clinic consists of a neuropsychiatrist, FNS specialist nurse, FNS specialist occupational therapist and an FNS specialist physiotherapist. When they are first seen in this clinic, some patients have accepted their diagnosis, while other patients report they do not recall their diagnosis or reason for referral. The decision to admit is then made collaboratively based on each patient's needs and the MDT assessment.

The referral process is outlined in Figure 1, and the criteria to be considered for treatment are as follows:

1. Definitive diagnosis of FNS by a neurologist.
2. Acceptance of the diagnosis, with no requests for further diagnostic investigations.
3. Willingness to engage in MDT programme.
4. Ability to work with a goal-orientated approach.
5. No current litigation related to symptoms (though this is on a case-by-case basis).

The MDT clinic assessment has a number of roles in addition to the usual clinical history taking. The lead clinician must build trust, take an inventory of symptoms and explain the diagnosis and the approach to treatment. During the assessment, interviewers and patients can begin to put together elements of a clinical formulation. For instance, a patient experiencing intermittent leg weakness might disclose a history of trauma with current symptoms of post-traumatic stress disorder (PTSD), so that 'leg buckling' occurs in response to particular triggers.

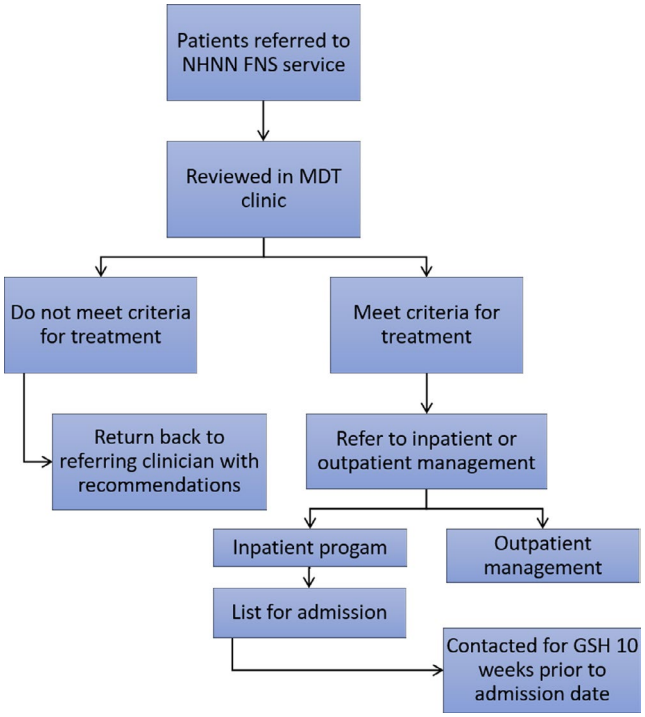

FIGURE 1 Flow chart showing the referral pathway for the IP program and GSH

The patient is encouraged to take responsibility for their own rehabilitation with professional support and guidance. By discussing the treatment programmes on offer, the clinician can gauge the patient's willingness to engage and come up with an estimation of the patient's suitability for treatment. At the end of the assessment, the patients are invited to suggest two or three goals they might like to work on when they start treatment. Patients accepted for the inpatient programme are contacted approximately 10–12 weeks prior to their admission date to start the QGSH.

3.1 | The Queen Square Guided Self-help programme

The QGSH is a course of Internet-based guided self-help. It runs for up to 12 weeks and includes original videos and patient worksheets, as well as signposting to existing published resources such as Neurosymptoms.org. It involves therapists guiding the patient to use a range of psychoeducational resources and guides to simple therapy activities, supported by one-to-one contact, such as brief telephone calls, at sparse intervals (Cuijpers & Schuurmans, 2007). Resources,

including the book 'Overcoming FNS' (Williams et al., 2011), are used according to clinical judgement and patient collaboration within a flexible protocol. Information is sent weekly by email, and content is delivered in the form of 11 modules built around video sessions on YouTube (see Table 2). The YouTube videos are not freely accessible; each link is sent to the patient by the QGSH therapist at the appropriate time in the therapy. Patients are supplied with complementary, CBT-based worksheets and exercises and are supported by telephone appointments by experienced clinicians: a senior occupational therapist (SH), a consultant psychiatrist in psychotherapy (MM) and a psychologist (CS). Guidance telephone appointments take place at 2- to 3-week intervals. The therapists are able to adjust the rate and ordering of the modules to best meet the needs of each individual patient. Adjustments such as sending resources by post are often made, as patients' ability to use electronic devices varies, especially if they are older.

The GSH therapists must build trust in a timely manner, explaining how the programme works and the importance of a collaborative therapeutic alliance. This also implies a therapy contract and outlines the boundaries of therapy. During the crucial first few weeks, the GSH therapist must develop a rapport, which can be difficult for patients with a history of negative interactions with healthcare providers. Symptom diaries and worksheet exercises at the start of GSH ensure that the patient's narrative is 'heard', and their symptoms are taken seriously. For patients who feel they have not been believed, this is an important component of the therapy. As well as psychoeducation, the therapist is checking patient acceptance of the diagnosis, since even patients who say they agree with the diagnosis of FNS often harbour doubts that their symptoms are really due to another condition, such as Lyme disease or mast cell activation syndrome. This is part of the process of exploring the patient's beliefs about what has caused and/or is maintaining their symptoms. They may link them to a recent life event such as bereavement or workplace conflict. There may also be cultural issues such as a belief in evil spirits or that their symptoms are simply 'God's will'. The topics covered are shown in Table 1 and include the following: introductory sessions on 'What are FNS and how do they affect your life?' and further topics including 'What is the five-areas approach?'; 'stress, symptoms and the body'; 'goal setting'; 'helpful and unhelpful thinking'; 'illness symptoms'; and 'other people managing pain and fatigue management' and 'dealing with low mood'.

TABLE 2 QGSH video titles

1. Introductory Session 1: What are functional neurological symptoms?
2. Introductory Session 2—Body, the role of the autonomic system and of stress, stress and symptoms
3. Goal setting
4. Introduction to the 5-areas approach (symptoms, behaviour and affect)
5. 5-areas approach—focus on cognitions—thinking and feelings
6. Anxiety and FNS
7. Fatigue and pain
8. Presentation of workings of the inpatient therapies and the MDT
9. Thinking about the self and others: Mentalisation for FNS
10. Mood problems
11. The role of medications
12. Avoidance in FNS

Setting 'homework' tasks is a key area to explore difficulties in collaborative therapy relationships that require the patient to take an active role. Homework raises important issues such as the patient delaying the return of their homework because of concerns about 'getting it wrong' leading to criticism or embarrassment. This can be addressed during the GSH to pave the way for the more intensive MDT treatment. The phone calls are also important for bolstering the patient's motivation for change, by engaging them in the clinical formulation and collaborative empiricism, that is, devising and testing hypotheses (Beck & Wright, 1997). For patients who are able to work directly with cognitions, during discussion of a Thought Record, the therapist can gently probe and challenge the patient's unhelpful thoughts. The phone calls also provide an opportunity to check in with the patient about their feelings about the therapy and review progress. The patient is then encouraged to set and work towards early goals in their rehabilitation. Finally, attention is paid to the ending of this phase of treatment, which includes realisation that it is not a 'cure all', and the process of handing over care from the preparatory to the inpatient team. The process of handover is one where the patient is encouraged to have a key role: rather than being passively 'handed over' within the treatment team, the patient is encouraged to inform the inpatient clinicians who first meet them what they have learnt and achieved during the preparatory therapy. This is important both for informing the clinicians and, more importantly, for giving the patient a key responsibility for their self-management.

3.2 | The GSH modules

Guided self-help videos and worksheets are structured into thematic modules. These are provided to patients electronically and supplemented by phone calls from the GSH therapists. Video clinics are being developed to flexibly replace phone calls. As a patient progresses through available modules, the programme is personalised for each patient by the therapist in terms of module ordering and rate of delivery. This is aimed at providing the best possible experience, while managing the complex needs of this patient group. Each module comprises a video session accessed on YouTube and a set of associated worksheets for the patient to complete. These were produced collaboratively by the therapy team to provide an original set of materials. The worksheets were designed to complement the videos and were based, in part, on the 5-areas approach book (Williams et al., 2011), while respecting the copyright permissions given by its authors. The patients were invited to get hold of a copy of the book, and although this was 'optional', most of them did so. We now describe a module that illustrates how a fairly standard CBT approach is finessed to address the needs of this patient group, a philosophy that pervades all preparatory work.

In the 'Anxiety and FNS' module, the basic principles for discussing anxiety are implemented as follows: (a) collaborative case

conceptualisation, whereby patient and therapist look beyond the list of current symptoms to determine the predisposing, precipitating and perpetuating factors; and (b) collaborative empiricism, whereby patient and therapist pool their experience and knowledge in an ongoing process of generating and testing hypotheses.

Some patients with FNS describe feelings and behaviours recognisable as 'anxiety', but they would not describe themselves as 'anxious', while some symptoms that clinicians recognise as anxiety are simply direct bodily experiences far from psychological concepts. 'Anxiety' in the context of FNS is complex and needs to be explored as it can be a triggering factor, or a consequence of symptoms. One patient may recall that everyone in the family was anxious as a result of a tragedy such as the death of a child, while another may recall childhood anxiety alongside other difficulties such as elective mutism. Patients who have lived through trauma may be experiencing the symptoms of PTSD, while others may have social anxiety, specific phobias, obsessive–compulsive disorder, or panic disorder. Anxiety can also be a direct consequence of FNS. Symptoms such as intermittent leg weakness, numbness or paralysis can cause embarrassment, anxiety, panic, and social isolation. Over time, this can drive negative cognitions and low mood.

The 'Anxiety & FNS' GSH component has two short videos and a worksheet. The videos are a presented as slides and a small 'talking head' in the corner (Figure 2).

The sections are as follows: (a) What is anxiety and why is it a normal part of life?; (b) how anxiety manifests; (c) When is anxiety helpful and when is it not helpful?; (d) anxiety in people with FNS; (e) ways you can help yourself; (f) an example; and (g) a little exercise for you to do. The first video aims primarily to educate the patient, while the second video is more interactive. The concept of the vicious cycle that causes stress is worked through using an example. The viewer of the video is invited to think of the interplay of cognitions, moods and bodily symptoms they might experience whilst sitting in a dentist's waiting room. The last section, 'a little exercise for you to do', ties in with the accompanying worksheet (Appendix 1) and contains a short mindfulness task. The patient is invited to rate their anxiety on a 0–10 scale, then focus on something in the natural world such as a tree or a leaf or flower. They are asked to focus on this object and observe the fine details, then re-rate their anxiety on a 0–10 scale. The final exercise is a symptom diary that asks the patient to develop the habit of analysing their thoughts, emotions and behaviours at the point of symptom onset.

The 'Anxiety & FNS' module has been well received as many patients with FNS have not previously made the link between anxiety, stress and their symptoms. Sharing the example of the dentist's waiting room can open up a fruitful discussion. During the course of the QGSH, some patients have expressed a wish to 'see' the therapist they are interacting with, and the talking head embedded in the video allows them to see the therapist talking through the slides. The format and delivery of this and other modules is subject to ongoing informal reviews.

3.2.1 | Engagement with the QGSH

In the 35 months the programme has run, from January 2017 to December 2019, 191 patients have taken part in the inpatient FNS programme, and 122 of these had taken part in the QGSH. The rate of completion of the QGSH varied between patients but, for these data, 'taken part' is defined as at least one email response by the patient. Demographic information is summarised in Table 3.

All patients referred to the IP programme were referred to the QGSH, but in small number of patients, there were issues with literacy, access or, unusually, urgency of admission, leaving no time for QGSH. Patients who did not respond to the invitation email nevertheless progressed to the inpatient programme; that is, QGSH did not have a screening role.

3.2.2 | Qualitative data

When the online service was first used, patients reported informally that interacting with the therapists reduced their anxieties about FNS treatment, in particular their concerns about stigma and the

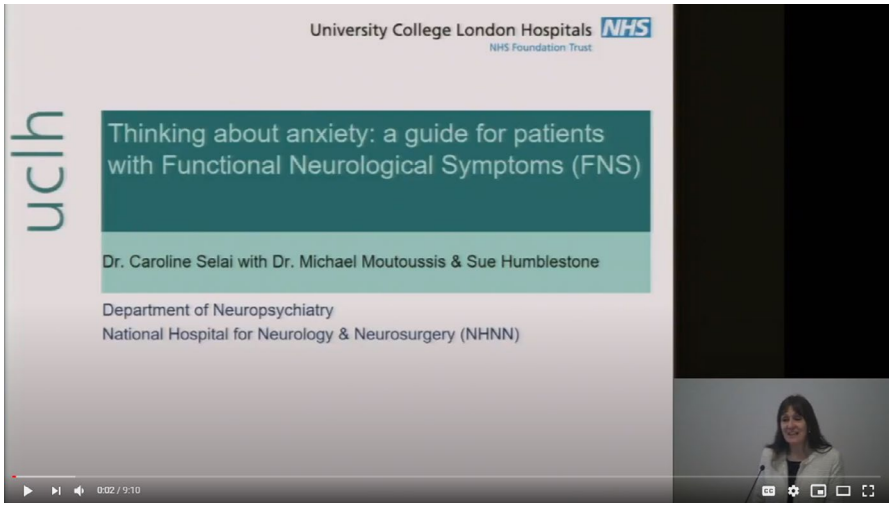

FIGURE 2 The first video for the 'Anxiety and FNS' module

TABLE 3 Demographic data on patients who took part in the FNS programme

Patients admitted to inpatient FNS programme	191
Male (%)	63 (33%)
Female (%)	128 (67%)
Patients who took part in GSH	122

attitude of staff. A number of patients talked about their previous negative experiences of diagnosis and unhelpful interactions with healthcare professionals. Conversations with the QGSH therapists explored these experiences and helped to reassure these patients. Although it was an 'optional' extra, almost all patients participating in the QGSH got hold of the book. The feedback from patients was overwhelmingly positive; that is, the QGSH had been helpful.

3.2.3 | Preliminary assessment of the outcomes of Queen Square GSH

We have embarked on a more comprehensive assessment of outcomes. Unfortunately, data collection was halted due to the COVID-19 pandemic. We present here a summary of our initial assessment of the outcome of delivering the QGSH to a sample of patients. We developed two study-specific outcome measures, and the full details of the development and psychometric testing of these scales are outside the scope of this manuscript. We developed a PROM and a CROM.

3.2.4 | The Patient-Rated Outcome Measure

The PROM has 31 items rated using ordinal 5-point Likert scales of 'strongly disagree' to 'strongly agree', divided into four subsections: (A) knowledge of FNS, (B) experience using the PTP materials, (C) whether PTP helped the patient transition to the inpatient unit and (D) family involvement in FNS.

PROM: findings

Data were collected from 19 patients. Two-thirds of patients responded positively (agree or strongly agree) for sections A, B and C. Section 'A' was intended to test 'knowledge of FNS'. This section was the most consistent across patients, with no scores below 3. Section 'B' was intended to test 'experience using PTP materials' and included six items that assess the patient's feelings about different elements of the PTP. The overall sectional average was positive. All the patients felt that accessing the videos was easy (item 6). Section 'C' had six items aimed at exploring the transition from outpatient to inpatient therapy, and most items were positive, with a median of 4 or 5. Section 'D' focused on family involvement in FNS treatment and was the largest section with 12 items. Most patients chose to select 3 (undecided). From additional qualitative comments elicited, most patients reported they were 'uncertain' about D, that is, family involvement in FNS, and this is an area we will address in future.

3.2.5 | The Clinician-Rated Outcome Measure

The CROM has 15 items believed to address all elements of patient preparedness. They are as follows: (i) knowledge of FNS, (ii) engagement during the preparatory treatment, (iii) handover organisation, and (iv) overall competence for the inpatient therapy. Responses are given on an ordinal 5-point Likert scale ranging from strongly disagree (1) to strongly agree (5).

CROM: findings

The CROM was administered to 29 clinicians. While Sections 1 and 4 were answered positively overall with medians of 4, Section 3, describing handover from the QGSH team, had a low score. It would appear that our handover notes were not received by all members of the inpatient team. The QGSH team is currently addressing this.

3.2.6 | Summary of preliminary outcome data

After developing the PROM and the CROM, we collected data from a sample of clinicians (CROM) and patients (PROM). Results for the PROM subsections: (A) knowledge of FNS, (B) experience using the PTP materials, (C) whether PTP helped the patient transition to the inpatient unit, and (D) family involvement in FNS, all were rated positively by most patients except Section D, that is, questions about family involvement. Results for the CROM subsections, (i) knowledge of FNS, (ii) engagement during the preparatory treatment, (iii) handover organisation, and (iv) overall competence for the inpatient therapy, were positive except for (iii) handover to the inpatient team. We are making changes to address both of these areas. The QGSH requires fuller assessment of outcomes, and this is the focus of ongoing research.

4 | DISCUSSION

The Queen Square Guided Self-Help programme is an Internet-based introduction to rehabilitation for functional neurological symptoms, delivered to a group of tertiary care patients with very significant disabilities, by experienced clinicians. Its main aim is to initiate patients to a CBT-based rehabilitation approach, which offers its own clinical benefits but, crucially, mainly aims to optimise the efficacy of subsequent inpatient multidisciplinary treatment. The QGSH has been developed and applied since 2015 and is being evaluated and developed on an ongoing basis. It has not only a clinical impact, but also an academic and educational one, as its associated projects form an excellent arena for graduate student participation in service evaluation.

The experience of the QGSH has highlighted how complex FNS can be to treat, particularly in a tertiary referral centre, and has emphasised the importance of flexible, personalised therapy. To optimise patient engagement and treatment, it has been important for the QGSH therapists to be able to individualise the therapy as to the selection, order and rate of delivery of modules to fit the patient's needs. Based on the literature and our clinical experience, we have taken a cognitive rehabilitational approach, but our interactions with patients are also viewed within a psychodynamic lens; i.e. we consider transference and countertransference feelings and discuss them in clinical supervision.

This consists of a 'psychodynamic prism' of thinking and understanding. Taken together, these approaches are particularly important for developing a positive therapeutic relationship, and so promoting patient engagement and satisfaction.

The preparatory therapy includes a number of worksheets and videos, which are continuously reviewed to ensure that they are clear and easily intelligible. As it is common for this patient group to feel that they have been dismissed or rejected by healthcare professionals in the past, it is particularly important that the videos and worksheets do not use words or phrases which could be interpreted as disrespectful by patients. Part of the review process is therefore to seek feedback that ensures that the language used helps patients feel understood and believed at all points throughout the programme. In the long term, it is aimed to make the materials easier to use through techniques such as making worksheets electronic for those patients who prefer them. This should keep in mind ease of access for patients with manual dexterity or (electronic) literacy issues.

Since the inception of the QGSH, we have found it to be an important addition to the inpatient programme, providing significant benefits to patients. At the same time, determining the most appropriate outcome measures for this heterogeneous group of patients is a work in progress. Many patients have reported that they have found the QGSH very helpful both in and of itself and in helping them to get the most out of the inpatient programme. The inpatient staff and therapists have also commented that they feel that patients are better prepared to work with the MDT by the QGSH.

In terms of future prospects, the QGSH provides an excellent springboard for service developments. Prior to the inpatient service being paused because of the COVID-19 pandemic in 2020, a total of 10 to 15 patients were taking part in the QGSH at any one time, across the three therapists currently in the team. COVID-19 has demonstrated the need for distanced and virtual approaches to reviewing and treating patients, including in cases where the risks of admission are unacceptable. The QGSH team are in discussions to develop GSH for FNS and medically unexplained symptoms as a stand-alone therapy, to be used as part of a 'stepped-care' approach. Even before the COVID-19 pandemic, the need for a service like this was clear from the increasing waiting list for the inpatient treatment, and there is evidence that GSH approaches can be effective in treating anxiety disorders and FNS.

We believe that the set of materials used in QGSH has the potential to provide significant benefits for patients with FNS and can support clinicians wishing to develop their expertise in treating FNS. It could help with the development of new specialist FNS services, for example for less disabled patients where QGSH can form the basis for completely stand-alone interventions where they have not existed before, something we are keen to support. We hope that the experience of our team can be used to help patients and clinicians to improve the provision of FNS services. Interested clinicians may contact us at UCLH.NHNN-GSHFNS@nhs.net to discuss access and use of the materials with potential for ongoing collaborations.

CONFLICTS OF INTEREST

None of the authors have a conflict of interest to declare.

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APPENDIX 1

ANXIETY & FNS: WORKSHEET

Thinking about anxiety: A guide for patients with functional neurological symptoms (GNS): To accompany videos 1 & 2

This is a worksheet to accompany a section of our Guided Self-Help (GSH) on the topic:

Thinking about anxiety: A guide for patients with Functional Neurological Symptoms (GNS)

There are two videos: Part 1 & Part 2.

As you watch the videos you will see reference made to three tasks

1. Task 1: Asks you to imagine going to an appointment with your dentist and to write down your thoughts.
2. Task 2: Invites you to rate how you are feeling on a 0–10 scale.
3. Task 3: Asks you to complete a diary over the coming week.
   a. These tasks are to help you to engage with the videos and help you to reflect on how life is for you
   b. There are no right or wrong answers
   c. You might like to get a pen or pencil now so you have something ready to write with!
   d. Are you ready to watch the videos..?
   e. Press Play and let's begin!

Task 1: In the video you are invited to think of a time when you had an appointment with your dentist. Here is the scenario

You made an appointment with your dentist because of a problem with your tooth. You are in the dentist's waiting room and you will soon be called in. You can smell the mouthwash and you remember that you are always invited to rinse your mouth at the end of treatment.

You start to have automatic thoughts.

- Can you think of some thoughts? Please note them down on your worksheet.

  These thoughts lead to bodily sensations.
- Can you think of some of the bodily sensations? Please note them down.

  This might affect your mood.
- Can you think of ways your mood might be affected? Please note these down.

  Finally all this might affect your behaviour.

  What might you do..? Please note this down.

Task 2

When you are feeling stressed or anxious or panicky:

Rate your feelings on a 0–10 scale:

Write down the number.....

Spend a few minutes doing something relaxing such as connecting with something in the natural world. Look at a tree or a flower. What do you notice about the leaves, the petals..?

Breathe deeply. Hold your breath and count: 1, 2, 3.

Now breathe out.

Rate your feelings on a 0–10 scale:

Write down the number.....

Task 3

Please keep a diary over the next week. Each time you feel 'panicky' please note down your:

- Thoughts
- Emotions
- Physical sensations
- Behaviour

Time when I felt panicky (date)	Thoughts	Emotions	Physical sensations	Behaviour

APPENDIX 2

DSM V DIAGNOSTIC CRITERIA AND ICD-11 CATEGORISATION FOR FNS (CONVERSION DISORDER)

DSM V Criteria

A. One or more symptoms of altered voluntary motor or sensory function
B. Clinical findings provide evidence of incompatibility between symptom and recognised neurological or medical conditions
C. Symptom or deficit is not better explained by another medical or mental disorder
D. Symptom or deficit causes clinically significant distress or impairment in social, occupational or other important areas of functioning or warrants medical evaluation

With specific symptom type:

Motor	Weakness or paralysis Abnormal movement (e.g. tremor, dystonic movement, myoclonus, gait) Swallowing, Speech
NES	Attacks or seizures
Sensory	Anaesthesia or sensory loss Special sensory (e.g. visual, olfactory, auditory)
Mixed	

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