**TITLE**

Sensory-motor rehabilitation therapy for task specific focal hand dystonia: A feasibility study

**ABSTRACT**

**Introduction**

Medical treatments have limited long-term effect in task-specific dystonia (TSD). Whilst evidence supports the use of rehabilitation, no randomised controlled trials (RCT) have been undertaken. This small-scale study determined the feasibility of implementing and evaluating a mixed sensory-motor TSD rehabilitative programme.

**Methods**

Participants with Writer’s (WD) or Musician’s dystonia (MD) were recruited from a movement disorder and hand therapy clinic. Feasibility measures were: recruitment rate, retention, session attendance, adherence to exercises. Self-report measures at 0, 3 and 6 months included: Arm Dystonia Disability Scale (ADDS), Tubiana and Chamagne Scale (TCS), Brief Illness Perception Questionnaire (BIPQ), Health Status (EQ-5D 5L), Clinical Global Impression Scale (CGI). Task performance was video-recorded at baseline and 6 months. At 6 months, interviews explored participant experiences of the intervention.

**Results**

Fifteen patients were recruited over 6-months (rate 2.5/month, MD = 8, WD = 7). Twelve people’s (80%) complete data was collected. The programme comprised a maximum six sessions plus daily home exercises. Nine completed the home programme at ≥ 75%. No adverse events were reported. Effect sizes at 3 and 6 months respectively were: ADDS 3 month = 0.28, 6 month = 0.23; TCS 3-month = 0.13, 6-month = 0.53; BIPQ 3-month = 0.38, 6-month = 0.71; EQ-5D-5L 3-month = 0.34, 6-month = 0.59; Video Analysis at 6 month = 0.78. Eleven (92%) improved on the CGI. Interviews supported acceptability of the intervention.

**Conclusions**

This intervention was feasible to deliver with high retention, adherence and acceptability. Improvements occurred across measures. This informs the development of future RCTs.

**KEYWORDS**

Musicians’ dystonia, writers’ dystonia, sensory-motor rehabilitation therapy, hand therapy

**ABBREVIATIONS**

ADDS (The Arm Dystonia Disability Scale)

BIPQ (The Brief Illness Perception Scale)

CGI (Clinical Global Impression)

MD (Musicians’ dystonia)

TCS (The Tubiana and Chamagne Scale)

TSD (Task specific dystonia)

WD (Writers’ dystonia)

**INTRODUCTION**

Task-specific dystonia is a subtype of dystonia in which an abnormal posture occurs during the performance of a specific, usually highly skilled task, such as playing a musical instrument (musicians’ dystonia) or writing (writers’ dystonia). It can be very disabling, especially for professional musicians, with up to 62% of affected patients unable to continue their performance careers.1 The pathophysiology and aetiology of task-specific dystonia is not completely understood. It is thought likely to be related to sensorimotor system alterations potentially caused by interaction between the continued repetitive practice of a highly skilled movement in the face of imposed intrinsic (e.g. fatigue or injury) or extrinsic (alterations in technique or mechanical demands) changes. Correspondingly there is experimental evidence for both motor and sensory dysfunction (such as altered inhibition within motor cortical areas and alterations in the delineation of the sensory homunculus representing the affected part)2 as well as a wider cognitive context which includes an abnormal attentional focus during performance, anxiety and perfectionism.2

Existing medical treatments such as oral medications (e.g. trihexyphenidyl) and botulinum toxin injections are limited in their long-term efficiency.3 There is an increasing interest in using specific rehabilitative techniques which include: sensory re-education,4- 8 sensory motor retuning,9-13 mirror therapy14 and slow down exercise treatment.15 However, randomised controlled trials (RCT) of these techniques have not yet been undertaken.

Given that there is pathophysiological evidence for mixed sensorimotor dysfunction in task-specific dystonia, our hypothesis is that a mixed sensory-motor rehabilitation approach would be effective in improving function. There is need for a full-scale blinded RCT to investigate the efficacy of such an intervention in improving the function and quality of life of persons with TSD. However, beforehand a feasibility study is warranted to ensure the operational components are appropriate. Thus, we had two main aims. The first aim was to assess the feasibility (patient acceptability and adherence) of providing a mixed (supervised and home based programme) of sensory-motor rehabilitative activities currently offered as “usual care” in an outpatient hand therapy practice. The second aim was to evaluate operational elements of the trial design related to participant recruitment, retention and suitability of the assessment process and outcome measures. To achieve these aims this study had several objectives (Table 1).

**METHODS**

**Study Overview**

This was a small-scale single group feasibility study. The intervention was delivered as part of routine clinical practice, at an outpatient hand therapy clinic, and the assessments were approved by the local ethics committee (North West London Research Ethics Committee 1. Ref: 11/LO/0307) and carried out at a specialist neurological hospital. Informed written consent was obtained from all participants. Figure 1 provides an overview of the study design and participant pathway.

**Participants**

The study recruited consecutive eligible participants over a 6-month period, from a movement disorder clinic at the National Hospital for Neurology and Neurosurgery and a private hand therapy clinic, London Hand Therapy. Participants were eligible for inclusion if they were: aged ≥ 18 years of age, with a diagnosis of task-specific dystonia affecting writing or musical performance made independently by two neurologists specialising in movement disorders (MJE, AS, AM, IP), and symptoms causing sufficient impairment for the patient to request treatment. Exclusion criteria were: the presence of another neurological (e.g. peripheral neuropathy) or musculoskeletal condition that could impair hand function, ongoing treatment with botulinum toxin injections into any muscles of the affected upper limb, and the receipt of hand therapy or physiotherapy in the last 12 months. Of those who met the inclusion and exclusion criteria, all accepted to participate in the study apart from three people who were declined by the research team due to funding limitations.

**The Intervention: Sensory-motor rehabilitation therapy**

The intervention was designed so that it could be implemented in publically funded clinical practice and included a self-directed home exercise program framed within clinical therapist encounters. For this feasibility study a specialist hand therapist with more than 18 years of experience treating task-specific dystonia (KB) carried out the mixed sensory-motor rehabilitative therapy. The intervention combined four previously published specific treatment approaches to TSD, and five generic hand therapy treatments. A summary of treatment approaches can be seen in Table 2. The treatment sessions were standardised, apart from minor changes such as accommodating positions to make them more comfortable, and notes were taken at each treatment session for all individuals.

The intention was for participants to receive a maximum of six therapy sessions over a six-month period: initial appointment (60 minutes), first follow up appointment one month after initial appointment (60 minutes), and then each further follow up appointment at six weekly intervals (30 minutes each). Participants were requested to undertake a home exercise programme which was integral to this rehabilitation programme. They were asked to complete a daily log by hand or electronically. The recommended amount of each exercise was indicated on the written home exercise log and patients were asked to accurately record the time they spent undertaking the exercises.

**Feasibility Outcomes**

Feasibility measures were: recruitment rate over the 6-month period, retention, attendance at therapy sessions, and adherence to the home exercise programme (quantified using the patient reported daily log). There is no guidance regarding the minimum intensity and frequency of rehabilitation required to gain an effect, however from a theoretical perspective it is more likely that an effect will be gained if adherence levels are high. With this in mind, together with clinical experience and feedback from patients as to what was a “reasonable” rate of adherence, we decided a priori that acceptable adherence was attendance at ≥ 75% therapy sessions and completion of ≥75% or more of prescribed home exercises. Adverse events were to be recorded in the clinical notes by the clinician and/or in the home exercise log by the patient. Participants were asked their opinion of the effectiveness of individual therapy components on a 3-point Likert scale (anchored with effective and not effective).

**Clinical Outcome Measures**

The following standardised and validated patient-reported questionnaires were collected at baseline, three and six months into the intervention:

1. The Arm Dystonia Disability Scale (ADDS) rates the severity of impairment in hand function across daily tasks such as writing, playing a musical instrument and handling utensils. It is designed to quantify disability on a scale of 0-100% (100% = no disability).21-24
2. The Tubiana and Chamagne Scale (TCS) rates the severity of impact of dystonia on musical performance from 0-5 (5 = return to concert performance).25-29
3. The Brief Illness Perception Scale (BIPQ) is a measure of the cognitive and emotional representation of illness. It ranges the threat of an illness from 0-80 and a higher score reflects a more threatening view of the illness.30
4. Health Status measured by EQ-5D 5L which includes descriptive assessment across five dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression) and a visual analogue rating of total health. These are then converted into an index value from 0 to 1 (1 = complete health).31
5. Clinical Global Impression Scale (CGI).32-34 This rates change from baseline impairment on a seven-point scale: very much improved, much improved, minimally improved, no change, minimally worse, much worse, very much worse. This was rated at three and six months.

At baseline and six months a standardised video recording was undertaken to capture a clinician rated assessment of change. Musicians were asked to play a piece that exacerbated their dystonia for two minutes and a mezzo forte legato scale of two octaves 15 times at a speed of eight notes per second (metronome paced). For the free playing the tempo was defined at the baseline assessment and the piece was repeated at the same tempo at six months. Participants with writing dystonia were video-recorded writing a standard sentence 10 times, writing five lines of interconnected ‘l’ with 10 letters per line. Two neurologists (MJE, LR) blinded to the treatment session rated videos according to the following scale: no impairment (1), mild impairment (2), moderate impairment (3), severe impairment (4). Scores were generated for both the predetermined sequence (interconnected ‘l’ or scale) and the free task production (writing sentence or piece).

**Qualitative Interviews**

All participants were invited to undertake a brief semi-structured interview to ask them about their experience of engaging in the hand therapy intervention and home exercise programme. These brief, audio-recorded, interviews were undertaken by the primary researcher (KB). They were transcribed verbatim, coded and thematically analysed.

**Data Analysis**

This was a feasibility study, and hence inferential statistical analysis and hypothesis testing of the outcome measures is not appropriate and thus was not undertaken.35 Both the patient characteristics and change in outcomes was investigated using descriptive statistics and the calculation of effect sizes (between baseline and 3 months; and baseline and 6 months) according to Cohens d.36 An effect size (ES) of 0.8 is considered large, an effect size of 0.5 is considered medium and effect size of 0.2 is small.37 Statistical analysis was run using SPSS (version 24).

**RESULTS**

Over the 6-month recruitment period 15 patients met the inclusion criteria and were recruited, eight with musicians’ dystonia and seven with writing dystonia.

**Feasibility outcomes**

The recruitment rate was 2.5/month. In terms of retention, 12 (80%) of the recruited subjects completed the study. Table 3 provides a summary of the sample demographic and diagnostic characteristics. Two patients dropped out of the study due to a lack of motivation (one before the commencement of the therapy, and another after two therapy sessions as they stated that they did not want to complete the home exercise programme). A third patient stopped the study after 10 weeks due to developing a shoulder tendinopathy on the non-dystonic side, this was not related to the intervention or participation in the trial. For those completing the study, there was a 97% attendance rate at therapy sessions. Of the 72 therapy sessions offered (12 subjects with the possibility of six sessions each) only two sessions were not attended due to significant personal events (family funeral, patient in labour). Nine of the 12 participants completed the home exercise programme at ≥ 75% (all writing dystonia patients, four (57%) with musicians’ dystonia). Two of the twelve (16.67%) reported finding the home exercise programme too arduous and too intense to complete (one from each patient group). No adverse events were reported.

**Clinical Outcome Measures**

Table 4 summarises the outcome measure results, at each time point, for the 12 participants who completed the study. The effect sizes demonstrated that there were small improvements from baseline in the patient reported Arm Dystonia Disability Scale (ADDS) at the two assessment points. There were small to medium patient reported improvements in the Tubiana Champagne Questionnaire, the Brief Illness Perception Questionnaire and perceived health status (EQ-5D 5L score); with scores on each of these measures continuing to improve over the timeline of the study. The clinician rated video analysis showed moderate improvements over time with sensory-motor rehabilitation therapy.

**Qualitative interviews**

All 12 participants who completed the study engaged in the interviews. The techniques reported by participants to be effective, neutral or not effective are shown in Figure 2 Patients affected by MD found the following treatments effective: sensory motor retuning (86%), slow down exercise therapy (71%) and mirror therapy, shoulder range of motion and hand strengthening exercises (43% each). Patients affected by WD found the following treatments effective: hand strengthening exercises (80%) and sensory motor retuning, shoulder range of motion and slow down exercise therapy (60% each). None of the participants reported either soft tissue massage or ultrasound therapy to be effective.

Three main themes were identified: (1) The impact of dystonia, (2) Individuals respond differently to different treatment techniques, and (3) Changes require persistence and can take time (Table 5).

***Theme 1: The impact of dystonia***

All the participants described the negative impact of dystonia on their lives, which resonates with the findings of other qualitative work38. In particular, the participants described the specific physical impairments they experienced which impacted upon their ability to carry out tasks and professional activities. This marked impact on people’s emotional well-being was striking which is not surprising given that these symptoms typically reach their peak at the high point of the musicians’ professional career and can render them unable to play and indeed at times never able to return to their profession. This impact on emotional well-being is in line with the findings of other studies which demonstrate a tendency toward perfectionism and anxiety in musicians developing focal dystonia.39 Interestingly subjects with WD often see the condition as ‘inconvenient’ rather than career threatening, likely because difficulties with writing can be compensated for more easily in employment compared to difficulties with playing a musical instrument for a professional musician.

**T*heme 2: Individuals respond differently to different techniques***

People’s perception of their response to specific treatment techniques varied. This variation in response differed over the timeline of the study. For example, some subjects initially found the exercises frustrating and with little improvement in their function, but reported noticing marked improvements over time.

Several participants commented that these rehabilitative treatment approaches were preferable to medical interventions such as Botulinum toxin: *“I had three sessions of Botox but I found it made my hand weak and not functional, I couldn’t do buttons up or hold a key or write at all and therefore I have not had any more. I’m now using a Bic biro with a lot of Coban tape to build it up and it really helps the feeling of freedom and ease of writing – my hand still sometimes gets tense and I need to shake it out but my forearm does not get tense now.” (010, female, WD)*

***Theme 3: Changes require persistence and take time***

Many of the participants reported that the changes in symptoms and function took time and required patience and persistence, and could sometimes be demoralising. For some the changes were small, whilst others noted larger improvements.

TSD is a complex condition that affects individuals in a variety of ways: emotionally, physically and in specific task performance such as writing or playing a musical instrument. Use of a variety of individual techniques in combination seems to assist most people, but this requires time and commitment from patients to actively engage in the rehabilitation process.

**DISCUSSION**

Here we have reported data from a feasibility study of a specific sensory-motor rehabilitation therapy programme for people with TSD affecting writing and musical performance. This intervention was feasible to deliver with high retention, adherence and acceptability to patients. Improvements occurred across measures, and were typically larger at the six-month compared to three-month assessment which lends support to an on-going therapeutic effect of hand therapy over time.

All patients who met the inclusion criteria and were invited to take part in the study agreed to do so. Perhaps the high acceptance rate was partially due to the hand therapy being funded by a grant and thus not incurring private patient fees. There are a range of published treatment approaches typically delivered alone in a high intensity experimental setting that are arguably difficult to translate into routine clinical practice. The sensory-motor rehabilitation therapy programme we employed in this study is one we have used in routine clinical practice for many years, and is specifically designed to incorporate a range of previously described hand therapy techniques using a small number of face-to-face treatment sessions and a home exercise programme. The results of this feasibility study demonstrated that this intervention is acceptable to most participants. Adherence to attendance at the face-to-face therapy sessions and to the home exercise programme was above our 75% threshold in 75% of the subjects. There were no adverse events reported related to the intervention.

One difficulty with designing treatment studies in patients with TSD is the lack of specific measures to assess symptom severity.1 In this study we used a range of patient reported and clinician rated objective outcome measures. Of these, the most promising outcome measures in this study with respect to effect size were the patient reported CGI and the clinician rated video. At the end of treatment 50% of participants (2 WD, 4 MD) reported a good outcome (self-rating of much improved or very much improved), with a large ES on the CGI. A slight tailing off from perceived benefit was noted at 6 months in comparison to 3 months on the CGI. This suggests that either the patient reported CGI or the clinician rated video of performance may be useful primary outcome measures in this patient group, with the Brief Illness Perception Questionnaire and health state as secondary outcome measures. These results demonstrate that in a future powered trial (alpha 0.05, 80% power), a sample size of 36 would be required if the primary outcome was the patient reported CGI (6 month mean 3.08, 3 month mean 2.58, SD 0.51); 54 for the clinician rated video score (6 month mean 1.89, baseline mean 2.50, SD 0.78); or 66 for the patient reported BIPQ.

When interviewed all patients reported that dystonia had a negative impact on their lives emotionally and in work and functional activities. The treatments that individuals found useful were dependent on the person with many preferring therapeutic approaches rather than medical interventions. MD patients reported that sensory motor retuning and slow down exercise therapy were the two most effective treatments followed equally by mirror therapy, shoulder active range of motion exercises and hand strengthening exercises. Hand strengthening exercises were reported as being the most effective treatment in the WD group with sensory motor retuning, shoulder range of motion exercises and slow down exercise therapy all equally being reported as effective. Time and persistence was required to note changes with some only having small and others having larger improvements.

While this feasibility study was not designed to assess the efficacy of this intervention, these results do provide supportive evidence of a positive treatment outcome in some patients across a range of outcomes. Uniquely compared to previous studies in this area we adopted a mixed rehabilitative approach, combining several specific and general therapies based on individual assessment and response. This approach is supported both by the patient reported Likert scales evaluating effectiveness of specific therapy techniques and the qualitative interview data; participants typically found more than one therapeutic approach to be beneficial. We believe that it is reasonable to propose that in a future clinical trial this mixed rehabilitative approach is used, rather than selecting a single approach for all patients.

**Study Limitations**

Ideally in establishing feasibility of a future randomised controlled trial we would have included a control condition, to determine the willingness of patients to be randomised, and likely retention rates for this group. Also, our sample size was small and we relied on self-report to assess compliance with the home exercise program. The hand therapy intervention was implemented by a single therapist and whilst this meant that the treatments were standardised this could be viewed as a limitation due to possible bias and lack of generalisability. The hand therapy intervention being funded by a grant the acceptance rate may have been artificially high. This may have also had an impact on participants being more motivated to attend the therapy sessions and complete the home exercise programme and log. The follow-up was limited to six months; ideally longer-term follow-up of these patients would be of interest, as the treatment timeframe for this condition is considerable and often management of the symptoms is the focus rather than cure. Finally, in addition to asking people about their experience of engaging in the hand therapy intervention and home exercise programme, it would have also been helpful to seek their views, and the views of the clinical researchers, about the study processes and design features (such as acceptability of the recruitment procedures and outcome measures) to inform the design of a future RCT.40

**CONCLUSIONS**

This intervention was feasible to deliver with high retention, adherence and acceptability. Improvements occurred across measures, and were typically larger at the six-month compared to three-month assessment which lends support to an ongoing therapeutic effect of hand therapy over time. The findings provide data to help support the design and development of a future controlled trial for rehabilitation in TSD.

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**FIGURES**

Figure 1 - Study design

Figure 2 - Effectiveness of specific therapy techniques (participant reported)

**TABLES**

Table 1 - Study objectives

Table 2 - Summary of treatment approaches

Table 3 - Clinical characteristics for recruited participants

Table 4 - Changes in clinical outcome measures

Table 5 – Qualitative results