The upper limb stimulation service pathway at Queen Mary’s Hospital

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Thanks to Helen Nelson (now at King’s Hospital) for her substantial contribution to developing our upper limb stimulation service pathway and introducing outcome measures.
Plan:

Local context of service provision

Wider context of service provision

Service pathway

Outcome measures

Limitations
Local context of service provision

Electrical stimulation treatment is provided for a number of PCTs across London, Surrey and Sussex for:

- Gait assist
- Strengthening of lower limb muscles, e.g. peroneal muscles following Ponseti treatment for children with CTEV
- Upper limb applications

The service has been running in its current (funded) form for approximately 4 years; it is growing.
Local context of service provision

Upper limb stimulation referrals are typically for:

- Reduction of pain from shoulder subluxation
- Relaxation of muscle spasticity (predominantly a short-term effect)
- Increase function

Ideally stimulation is used in a hybrid approach, e.g. with:

- Community physiotherapy for stretching/strengthening
- Orthotics for wrist stability
- Botulinum toxin for spasticity management

Crucial to have one clinician coordinating all interventions

Referrals are mainly for out-patients, but there is some in-patient work through the neuro-rehabilitation team. The main reasons that we see patients for use of upper limb stimulation are:

- Reduction of pain from shoulder subluxation
- Relaxation of muscle spasticity (predominantly a short-term effect)
- Increase function

Stimulation is often used as part of a hybrid approach, e.g. with:

- Community physiotherapy team for combined stimulation and upper limb stretching/strengthening
- Orthotics for wrist stability
- Botulinum toxin for spasticity management

Our centre has a Specialist Spasticity Management Service and Orthotics team (including a locum hand splinting specialist), we also strive to link with local physiotherapy and occupational therapy teams.

This collaboration with other interventions is particularly critical for upper limb stimulation, which is a therapeutic rather than functional application. Our team assesses, sets up, supports and monitors use of stimulation but it is not within our capacity to provide a therapy service. It is best when upper limb stimulation can be incorporated within a wider therapy programme, hence the need to link with other services. The majority of referrals come from therapists and so it is best when they can attend the initial assessment, to ensure our stimulation collaborates with their input, and they can monitor progress as they see the individual more frequently. Where there are multiple interventions it is crucial to have one clinician acknowledged as the coordinator.
Wider context of service provision

There is limited official guidelines and recommendations for stimulation in the upper limb.

- RCP National Clinical Guidelines for Stroke (2008) only suggest trial with shoulder pain and subluxation

However, a number of studies have shown functional improvements after stimulation, post stroke, e.g.:

- Alon et al (2007), Neurorehab and Neural Repair
- Chae et al (1998), Stroke
- Santos et al (2006), J Neurologic PhysTherapy

See reference list from Salisbury Upper Limb course

Although ES has been used for a number of years to treat UL impairments, there are limited official guidelines and recommendations for use. The RCP National Clinical Guidelines for Stroke (2008) suggest that for UL ES should not be used on a routine basis but trialled in patients with persistent shoulder pain and subluxation. This is a ‘down-grading’ since their 2006 recommendations, which advised using ES as an orthosis in certain circumstances, as the RCP felt that there was not any conclusive evidence for addition of ES to conventional treatment. There is currently no NICE guidance for use of ES in the upper limb. However, a number of studies have shown functional improvements after a period of ES. For example Alon et al (2007), Chae et al (1998) and Santos et al (2006), reporting on functional capabilities post stroke. The upper limb stimulation course run here at Salisbury provides a substantial reference list for upper limb studies.
Various studies have noted time effects of stimulation in the upper limb:

- Kamper et al (2006), *Paed Phys Therapy*, increase in active wrist ext. up to 3 months, others plateau at 6 weeks
- Maenpaa et al (2004) improved hand function persisted for at least 3 months

Improvements in functionality, decrease in tone and pain are likely to be observed by 3 months use.

Various studies have made note of time effects of stimulation:
- Kamper et al (2006) found an increase in active wrist extension range following an ES programme. Within the study some subjects showed little increase at 6 weeks but considerable at 3 months, while others saw range plateau at 6 weeks.
- Ozer et al (2006) ES and dynamic bracing seen to reduce UL spasticity in children with CP when used every day, but the change disappeared following 2 months of non-use.
- Maenpaa et al (2004) found that improved hand function following ES treatment in subjects with hemiplegic CP persisted for at least 3 months.

From our experience at QMH and these literature reports we would expect to see any likely improvements in functionality and decrease in tone and pain by 3 months use of stimulation.
Wider context of service provision

The lack of guidelines highlights the need for a clear protocol and time frame for any UL stimulation service.

Stimulation for the upper limb does not generally function as an orthosis.

While UL stimulation is a small portion of our caseload a standard approach is important.

- Allowing consistent treatment
- Providing a platform for evaluation and refinement

The lack of guidelines and recommendations highlights the need for having a clear protocol and time frame for any UL stimulation service. Unlike when used in the lower limb, stimulation for the upper limb does not function as an orthosis (with present technology) and is therefore not usually intended to be used long-term.

In this context, through experience over the past 4 years we have developed the following clinical pathway for our upper limb stimulation work. While UL stimulation constitutes a small proportion of our caseload we feel it is important to establish a standard approach that allows consistent treatment, and it provides a platform for evaluating and refining what we do.
Prior to appointment, the Arm Activity Measure (ArmA) questionnaire to be sent to the patient.

To be collected:
- Photograph of electrode positions (if FES indicated)
- UL Joint PROM/AROM
- Functional outcomes as appropriate
- Set goals for intervention

Funding agreed with PCT?
- YES
- NO

Service level agreement in place with patient’s PCT?
- YES
- NO

Letter to referrer, GP and patient

Assessment appointment

Setup appt: week 0
- +1 week
- +6 weeks

Review 1: week 1
- +6 weeks

Review 2: week 7
- +6 weeks

Review 3: week 13

3 month break from stimulation

Review 4:
- +6 weeks

Second ArmA questionnaire to be sent out 2 weeks prior to Review 3 appointment

Report to GP (and PCT if required)

If UL function has deteriorated, continue with stimulation and review patient every 3 months.
If UL function has remained the same or improved, discontinue stimulation unless there is a clear clinical reason to continue – this must be documented fully in the notes. In this case, review at 3 monthly intervals.

This gives the whole service pathway for orientation – the green boxes give stages of administration, the grey path down the middle shows the appointment structure and timescale, the red and blue boxes indicate evaluation tools/outcome measures at each stage.
We have a standard referral form, which we try to get most referrers to use to ensure we get relevant information; patient details for admin, but also the reason for referral (patient’s problems to be addressed), goals for FES intervention, clinical data including previous interventions (such as splints, botulinum toxin injections, surgery) or any planned interventions. We also request GP approval through the form.

As noted earlier, with GP approval we have SLAs in place with 23 Trusts in our region, allowing immediate booking of assessment. In other cases we need to make a funding request. Currently our waiting time from initial referral is approximately 8 weeks.

We also have a standard information sheet explaining what ES is, who may benefit (and contraindications), what the treatment will involve, the tests we may perform and possible risks. This is sent out with the appointment letter, along with a questionnaire that I will explain later.
The initial assessment explores the patient’s history, if possible including discussion with current treating therapist, reviews the patient’s concerns with upper limb movement, function and pain, and expectations for treatment. The upper limb is assessed. Stimulation is tested – selecting application based on assessment, patient concerns and history. If a positive response is seen (or indications of potential) and the patient is happy with sensation and capable to use the equipment then setup appointment is arranged.

At setup the first set of outcome measures is collected – establishing a baseline for future comparison. The stimulation is re-applied and the patient is taught how to apply the equipment and seek the correct response. At this stage we establish goals for the stimulation intervention, which will be crucial for assessing progress. In some cases the assessment and setup are very simple so can be combined in one appointment, however both stages (including appropriate assessment) can be time consuming, hence having the standard approach of two appointments. This also gives the patient time to consider the treatment before beginning use. As with lower limb work, we have the first review after one week of use. This gives opportunity to address any problems with using the system, allows us to check that patient is coping as they have built up use over the week, and then we set a programme of use. This is usually a relatively brief appointment.

Our standard approach is to have two blocks – one block of 3 months using the stimulation, then 3 months without stimulation. We have a review half way through the 3 months of use, to check progress (repeating outcome measures/assessment) and consider any necessary changes to the stimulation setup. This is also a useful opportunity to review how stimulation is fitting with any therapy programme and other interventions. If any substantial changes are required then we may revise the time plan, otherwise at the end of the three months we repeat the assessment/outcome measures and the patient returns the equipment.

The 4th review is held to assess the upper limb following 3 months non-stimulation. The review is carried out in reference to the original goals for the intervention. As well as the patient’s perception of changes over the course of treatment this is where it is crucial to have appropriate assessment tools/measures to be able to compare with previous. If upper limb function has been maintained or has improved then we would normally advise not resuming stimulation, and would discharge them from the service and report the episode of care to the GP. If function has deteriorated we assess whether this links with likely stimulation effect and resume stimulation if appropriate. For these cases we would then have an on-going plan of review every 3 months.
As already mentioned, within the pathway we have set points for assessing upper limb joint range of motion and collecting appropriate outcome measures; at setup, 7 week, 3 month and 6 month reviews. A consistent assessment approach, with standardised measures of function, is important to guide the treatment. I will now go through the various assessment tools that we have adopted.
Arm Activity Measure (ArMA) questionnaire

- Functional questionnaire developed by a neuro-physiotherapist for stroke patients
- Split into 2 parts
  - Caring for their affected arm (cleaning, dressing and positioning)
  - Using their affected arm (activities of daily living)
- Comparison before and after intervention

Experience with neurologically impaired patients in the Gait Laboratory at QMH has shown that some patients find their ability decreases under the stress of having to perform at the appointment. In these cases in particular (but appropriate for all patients) it helpful to monitor the effectiveness of the ES through a patient-completed questionnaire. This is routinely done with patients receiving FES for the lower limb during walking through a mobility questionnaire developed by the Gait Laboratory team. The 2009 RCP guidelines on the management of Spasticity with Botulinum Toxin presented a list of suitable outcome measures for assessment of the upper limb including the Arm Activity Measure (ArMA, Ashord et al 2008) developed specifically for the assessment of upper limb function in people with hemiparesis. The questionnaire is sent out prior to the assessment, with the patient being asked to complete and return it to us before attending. This allows us to gain insight into their impairment beyond what they are able to report at the session, with questions relating to care of the affected arm and ability to complete daily functional tasks. We request repeat completion of the questionnaire before the 3 month and 6 month reviews, to assess changes in their perception of the limb at those stages of treatment.
At the assessment we carry out static examination of the arm - shoulder, elbow, wrist and fingers – considering passive and active range, and presence of increased tone. We have considered goniometric measurement (as we do for lower limb assessment) but currently find the most practical option is to video the movements relevant to the intended stimulation, and this allows visual comparison with repeated assessment at the review appointments. If the patient has very limited active movement this videoing may be the only form of ‘outcome measure’ that is possible.
If there is some basic functional ability then we try to use standardised tests of manual dexterity. We have adopted four tests to cover different ranges of functional ability. Before I go through our flow chart for selection it’s probably helpful if I briefly explain each test – next slide/video
Outcome measures

The Box and Blocks (BXB) test (Mathiowetz et al 1985, *The American Journal of Occupational Therapy*) is a test of gross manual dexterity, primarily at the hand but also requiring some shoulder and elbow movement. The subject is asked to transfer as many blocks as possible from one box to another with the movement over a central reservation. The score is the number of blocks moved in 1 minute.

The Nine Hole Peg Test (9HPT, Mathiowetz et al 1985, *The Occupational Therapy Journal of Research*, Grice et al 2003, *American Journal of Occupational Therapy*) is a quick, simple test of finger dexterity, with limited requirement for arm movement. It consists of a peg board into which 9 small pegs must be placed one-by-one and then removed, and is scored as the time taken to complete the test.

The Action Research Arm Test (ARAT, Yobatiran 2008, *Neurorehabilitation and Neural Repair*) measures arm and hand motor function through grasping, gripping, pinching, reaching and gross movements. The assessor scores each task on a 4-point scale, based on time to complete each task and quality of movement.

The Jebson Taylor Hand Function Test (JT, Jebson 1969, *Archives of Physical Medicine and Rehabilitation*) measures hand and arm function through a number of tasks associated with common activities of daily living, with the score being the time to complete each task.

Although not a standardised test, we may also video the patient performing other specific tasks, for example grasping, reaching and releasing different size objects (e.g. some of the ARAT objects, in addition to BXB, if the full ARAT test would be too demanding for their ability).

For each of these tests we have developed standard laboratory protocols for collection and scoring, based on the published recommendations for each test. We video the completion of each test, to allow scoring after the assessment and visual comparison of the quality of movements between sessions. In all the tests both arms are assessed, the non-affected first to get a baseline (bearing in mind which arm was ‘dominant’ before injury). Some of the tests have published ‘normal’ data for comparison and recommendation of what constitutes a clinically significant change in score, but we would be cautious in using such figures and we primarily use the scoring for comparison over time for each individual.
The 2009 RCP guidelines on the management of Spasticity with Botulinum Toxin suggest the Action Research Arm Test and the Nine-Hole Peg Test as useful focal measures for the upper limb, so we would consider these tests first – 9HPT for hand fine motor control without requiring much arm movement, ARAT for a wide range of fine and gross motor control tasks of the hand and arm. If the patient has some gross grasp and release function but insufficient shoulder movement for the ARAT we would consider the Box and Blocks Test. Then for subjects who have higher levels of function or have made progress in the other tests we may introduce the Jebson Taylor Test of hand and arm function.
It would be possible to use subjective muscle strength testing, for example using the MRC scale, but Chris has recently been developing a standard protocol for quantitative grip and pinch strength testing using a dynamometer. We have begun to use this for some patients where weakness of grip accompanies problems with selective wrist and finger extension, as an assessment of general hand function and selective control. (The dynamometer that we use is not the standard design reported in literature studies so comparison with published normal datasets is limited.)
Outcome measures
X-ray for shoulder subluxation assessment

For cases of shoulder subluxation and pain we primarily use assessment of range of movement, rather than the functional tests I have just described. However, if possible we also arrange an X-ray of the shoulder before assessment and then later during treatment, both with and without stimulation. Interestingly this has shown us that there is often minimal sign of subluxation – indicating that it can be very hard to gauge presence of subluxation from external palpation. This emphasises that the main reason for treatment is pain, rather than reducing subluxation.
Outcome measures
Video of response to stimulation, and active range

Finally in terms of assessment tools we will often video the response to stimulation once a treatment plan is decided, and comparative active movement. If at review the patient feels they are not getting as good a movement with stimulation as we achieved initially the video can be a helpful reference, and may indicate need for change of setup/further education of electrode placement and ‘hunting’ for the response. This is particularly useful in the team environment if the reviewer was not the one who set the system up.
Limitations

- Time taken to access collaborative splinting
- Apprehension about stopping stimulation for 3 month block
- Differences in hand function reported between home and clinical environment
- Good movement pattern but difficulty in structuring coordination of treatment
- Establishing realistic expectations
- Lack of evidence for most effective stimulation time

The pathway just described has generally worked well, however there are various issues that have arisen:

While we stress the need for collaboration of FES with other interventions we have found, in some instances that by the time a patient has been seen for assessment and provision of an orthosis the 3 month block of stimulation has finished.

Some patients can be apprehensive about stopping the stimulation after 3 months. For example in cases where the stimulation has had an apparent effect to help relax a hand with notable tone the patient can be worried that tone effects may worsen. Also, in some instances the stimulation has served as a focus for rehabilitation work on the arm, prompting them to give daily focus to the arm which they feel they will not be able to sustain once the stimulation stops. In these cases we try to reassure the individual that if the limb is becoming notably worse in the 3 months of no stimulation they can contact us for an earlier review. The small proportion of patients that resume use after the 3 months off, and then become longer term users, have generally been those who benefit from tone management, rather than increase in active function.

Some patients report very different function at home compared to when attending for appointments, for example with the hand becoming much stiffer, so that stimulation has reduced effect. In these cases it becomes hard to check that stimulation is providing the best action, and limits the effectiveness of our outcome measures.

Again relating to coordination of interventions, we have had some patients who show good patterns of movement with stimulation, but lack of a suitable therapy programme limits the usefulness for ongoing rehabilitation.

It can be difficult to establish realistic expectations. The outcome measures we use are for relatively basic functional tasks, whereas patients may be hoping to return to much greater functional levels.

Our standard approach is to recommend 30 minute blocks of stimulation, two times per day. With a lack of evidence for stimulation time/dose we are concerned that longer periods of stimulation may give greater benefit, but this has to be balanced with the practicality of what an individual is able to achieve in a day.
Thank you