Fifteen minute consultation: Management of the upper limb in unilateral cerebral palsy.

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Abstract:

Children with unilateral CP (UCP) have complex health, education and social care needs. Delayed gross motor milestones are the most common presenting feature, and much of the early management focuses on gross motor skills and lower limb management. In later childhood, adolescence and adulthood, upper limb function has significant impact on activity, participation and independence. There is clear pathophysiological rationale and emerging clinical evidence that earlier intervention to improve upper limb function is beneficial. Whereas most children with UCP are managed in secondary care, it is recommended that the assessment and delivery of specialist intervention for the upper limb occurs at a regional centre.

Introduction:

Unilateral cerebral palsy (UCP), or hemiplegia, affects approximately one third of all children with cerebral palsy, occurring in 1 in 1300 live births¹. Children are often physically less impaired than those with bilateral CP, but frequently exhibit difficulties with attention, concentration, learning and self-esteem as well as visual field defects and sensory inattention^{1,2}. Although some children have moderate or severe learning difficulties (particularly associated with severe epilepsy), many have normal cognition and attend mainstream school. With the current limitations in NHS resources, there may be little input from community health services for these children with complex needs.

Pathophysiology:

The clinical presentation depends on the site, severity and timing of the insult. Vascular causes are common; unilateral genetic causes of cortical malformation are rare.¹

UCP is a developmental disorder: whilst the insult to the developing brain is static, it impacts ongoing brain development. At term, there is bilateral projection of the corticospinal tract (CST) which due to activity-dependent competition reorganises to a predominantly crossed projection by age two years. Post-lesional CST re-organisation also occurs, either around the lesion within the affected hemisphere, maintaining the contralateral projection, or alternatively with loss of this projection but retention of a substantial ipsilateral projection from the undamaged hemisphere. The latter pattern of reorganisation is associated with poorer hand function and often the presence of pronounced mirror movements. In addition, it is increasingly recognised that in UCP there is a “less affected side” rather than an unaffected side.³ Presentation:

Children who develop UCP due to perinatal stroke may present with peri-natal seizures and encephalopathy, or with motor delay and emerging lateralised motor signs. There should be a high index of suspicion where there is early hand preference or asymmetry of movement. Parents often report that they had concerns before a diagnosis was made.⁴

Clinical assessment

Clinical emphasis is often on motor impairment but consideration of the child, in the context of their family, with respect to the ICF-CY domains is key to appropriate management.^{5,6} It is crucial to consider co-morbidities and their impact including epilepsy, associated neurodevelopmental difficulties, autism spectrum disorder, ADHD, concentration, processing, vision and specific cognitive needs. These may impact more on function and participation than motor impairment. Interventions to support motor impairment may not be effective if these co-morbidities are not recognised and addressed.^{4,7} (Figure 1)

History:

Begin by reviewing the history including antenatal and birth history even if the child is referred with an existing diagnosis. Check parental understanding of the diagnosis, family history and social support.

History should include a developmentally appropriate assessment of participation and activities of daily living. Clinical questionnaires have been developed for this and may be used as adjuncts. (e.g. ABILHAND-Kids: <http://www.rehab-scales.org/abilhand-kids.html>)

A problem-orientated approach is recommended. What are the current concerns? What does the child have difficulty with? What are their short and long term goals? Which activities do they participate in at school or at home? Specifically ask about pain.

Further management should be guided by:

- Understanding of current services engaged: physiotherapy, occupational and speech therapy, and educational support including previous detailed cognitive assessment or existing education, health and care plan.
- Review of previous and current orthoses, and interventions, including their perceived benefit.

Examination:

Complete a developmentally appropriate examination to elicit neurological features^{8,9,10,11,12,13} (Table 1). Observation of the child at rest and in spontaneous activity should start in the waiting room. Observing arm posture at rest, during walking and running and hand function during everyday tasks and play, is as valuable as structured examination (Table 2).

A variety of structured clinical assessments have been developed and validated (Table 3).

Key questions are:

- Does the assessment test capacity (what the child is able to do) or performance (what they usually do)?
- Is it assessing use of the affected hand or bimanual use?

Video recording is recommended even if not mandated by the assessment.

Investigation:

MRI is the investigation of choice if there is question regarding differential diagnosis.⁴

Understanding site, severity and timing of the lesion may help with prognosis and anticipated co-morbidities.

EEG should be considered if there is a history suggestive of epileptic seizures, but should be interpreted in the context of any underlying structural abnormalities by an experienced neurophysiologist.

There is no indication for detailed thrombophilia screen^{4,14}; however, clotting studies may be indicated for acute peri-natal stroke to identify correctable clotting abnormalities (e.g. secondary to sepsis.)

Management:

Therapy interventions for the upper limb in UCP:

Many therapy interventions are used in UCP;^{15,16} there is a re-assuring drive to develop the evidence base for these. The major challenge is that the evidence-based dose required with current clinical resource (funding and therapist expertise) is often unachievable through therapist input; hence, parent-delivered home-based programs with therapist support are attracting increasing interest. Debate regarding the relative merits of modified constraint induced movement therapy (mCIMT) and bimanual therapy has now diminished: both interventions are effective though factors such as the child's presentation, developmental stage and awareness of the more-affected hand and

the mode of delivery may influence the intervention chosen. Combinations of interventions are often used. With mCIMT, it is the intervention to support the function of the more affected hand, rather than the constraint per se that is crucial. Careful consideration of the method and duration of constraint of the less-affected arm is essential. The authors recommend following evidenced based protocols of mCIMT and ensuring that the child is not distressed during therapy.

Therapy should be fun, play based (with high and low-technology approaches), task-specific and include repeated practice. It should be tailored to the child's individual interests. Different models of provision (home-delivered by parents or therapist, at schools, and therapy camps) all have reported evidence of benefit.

How to match early therapy approaches to pathophysiology, clinical phenotype and hypothesised CST re-organisation remains unclear. Early intervention influencing re-organisation could be beneficial or harmful.¹⁷ Whilst there is some evidence of benefit in the literature for "baby CIMT", there remain important questions with respect to a safe time window.

Practical occupational therapy support is required, particularly at times of transition. When moving from primary to secondary education, significant issues (e.g. mobility around school, carrying a heavy school bag, changing for PE, using equipment in practical lessons) may be addressed once identified through good communication. Educational progress may be impaired by unidentified specific learning difficulties (e.g. processing speed, working memory) or there may be practical issues such as speed of writing.

For adolescents, moving on to college or independent living in adult life, receiving support for life skills and adaptations for independent living can be difficult. Recognising challenges and signposting to peer support is highly valued.¹⁸

Orthoses:

Evidence for orthoses in children with UCP is limited.¹⁹ Functional splints (for example neoprene, lycra) aim to provide some support to the position of the arm or part of it, improve sensory awareness, proprioception and facilitate use of the hand. Functional taping is unlikely to provide support but may improve sensory awareness; evidence of benefit is currently anecdotal.

Resting splints are prescribed to provide stretch, reduce pain, or improve hygiene. They may be used with other interventions such as botulinum toxin treatment or post-surgery. Serial casting is used to provide prolonged stretch.

Always check that the child and family understand what the splint is for, and when to use it. Is it fit for purpose? Does a functional splint improve function? Is a resting splint well fitted and comfortable?

Medications:

Systemic medications (e.g., baclofen and trihexiphenidyl) are prescribed, particularly for pain associated with dystonia or spasticity. Choice of medication should be related to movement pattern. Dosage should start low, and escalate gradually with careful monitoring of adverse effects.⁷

Botulinum Toxin:

Upper limb injection for spasticity and dystonia is widely used, but is off license, except for triceps surae. Evidence of benefit is limited to use in conjunction with other interventions, in particular goal directed therapy or orthoses.²⁰ Assessment needs to identify if the spasticity or dystonia is the “rate limiting step” impacting on function or if it is causing another problem such as pain. Unmasking underlying weakness, failing to recognise sensory inattention and non-neural tissue changes may explain lack of benefit. Careful management of parental and professional expectation is required. The treatment is temporary and if beneficial may need repeating; however effects may be long lasting if reduction in tone by toxin in combination with therapy unlocks new motor learning and provides an opportunity to strengthen antagonists.

Orthopaedic Surgery

Surgical intervention is often considered in the older child or adolescent; non-neural changes, such as muscle shortening, problematic fixed contractures and joint instability (especially in the thumb) are the main indications. Muscle lengthening, joint arthrodesis and tendon transfers may be considered. Typical goals of surgery include position, hand hygiene, comfort in dressing and cosmesis.⁹

Principles of intervention and delivery of care:

Prior to treatment there must be clear discussion regarding the implications of what the intervention entails and expectations for the outcome.

- Will it achieve their goals?
 - Does the child have the same goals as their parents, the local therapist and the provider at the regional centre?
- Is the timing and setting of the intervention appropriate?
 - Consider other issues for child and family and resource of the supporting local team.

Objective review of the outcome informs future care. If the intervention is not beneficial, evaluate why. (Figure 2). A clear care pathway with communication between services is essential.

(TEXT BOX 1)

Conclusion:

The current climate of resource limitation impacts on care for this important group of children with complex neurodevelopmental profiles. Regional specialist clinics and clinical networks can provide effective local delivery of care under guidance from regional specialist services.

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Table 1: Neurological Features in Unilateral Cerebral Palsy.

"Positive" features	"Negative" features	Other
Spasticity Dystonia Dyskinesia Chorea Athetosis	Weakness Sensory disturbance Sensory inattention	Non-neurological tissue changes (e.g., muscle shortening, poor bone growth, reduction in joint range of movement.) Visual impairment (hemianopia)

Table 2: Structured approach to upper limb examination in UCP:

		Clinical Tools	Top-Tips
Observation and overall description	Posture at rest and during activity	MACS (Manual Ability Classification System) ⁸	Observation is critical: “you see and feel dystonia, and feel spasticity”
	<ul style="list-style-type: none"> Shoulder elbow forearm wrist thumb fingers. 	House Thumb ⁹	<ul style="list-style-type: none"> Is there evidence of dyskinesia – chorea, athetosis? Are there mirror movements?
	Assessment of spine for scoliosis.	Zancolli Scor ¹⁰	Note if the child is deliberately stabilising their arm, sitting on it? Hiding it -are they concerned re: appearance?
	Dystonia		
	Dyskinesia		Note sitting position, truncal stability. <ul style="list-style-type: none"> Does dynamic increase in tone impact on balance?
	Mirror movements		
Tone	Palpation of upper limb. Goniometry:	Modified Ashworth Scale (MAS) ¹¹	Feeling for “spasticity”
		0 No increase in muscle tone	
	Passive range of movement – shoulder, elbow, forearm, wrist, thumb and fingers.	1 Slight increase in muscle tone, manifested by a catch and release or by minimal resistance at the end of the range of motion when the affected part(s) is moved in flexion or extension	Is the wrist position secondary to wrist flexor tightness or extensor weakness?
	Dynamic catch – measured and recorded.	1+ Slight increase in muscle tone, manifested by a catch, followed by minimal resistance throughout the remainder (less than half) of the ROM	Are there fixed contractures, with muscle shortening “non-neurological muscle changes?
	Evidence of clonus.	2 More marked increase in muscle tone through most of the ROM, but affected part(s) easily moved	Volkmann’s angle (angle of wrist flexion where fingers still fully extended) As you extend wrist often fingers flex due to shortening of finger flexors (PIP joints = FDS, DIP joints = FDP)
		3 Considerable increase in muscle tone, passive movement difficult	
		4 Affected part(s) rigid in flexion or extension	
		Tardieu Scale ¹²	
		Measure full PROM (=R2) and angle of dynamic catch (=R1) Dynamic component = R2-R1	
Power	Active range of movement - shoulder, elbow, forearm, wrist, thumb and fingers.		Typical pattern of shoulder flexor weakness, supination and wrist extensor weakness.
			Watch for shoulder internal rotation or elbow flexion (biceps activity) on attempted forearm supination.
			Thumb/ finger strength.
			Grip strength.
			Is the pronated position of the forearm due to pronator spasticity or shortening, and/or supinator weakness?
Sensory awareness	Visual field assessment	Formal ophthalmology and orthoptic assessment recommended.	Formal sensory examination difficult; 2 point discrimination often unreliable.
	Reported sensory inattention		History and observation often more helpful.
Functional assessment	Structured assessment, or clinical observation of play or activities	MACS (see Table 4 for other detailed assessments)	Release often harder than grasp. How does wrist position affect this?
	Spontaneous and prompted use of the more affected side.		Speed of task completion; assess less affected hand also – handwriting?

	Performance vs capacity?		What is the level of use as an assisting hand? What is the potential for improvement? Do the child and family understand the level at which the more affected hand may be used now and in future?
Other	General developmental assessment.	Strengths and Difficulties questionnaires (SDQ)	Evidence of language, communication or learning difficulties? Are the toys/ activities the child chooses age appropriate?

Table 3: Structured assessments used to assess upper limb function.

Assessment	Assessment Category	Description	Age	Time to Administer	Time to Score	Unimanual i.e. just one hand used in tasks Bi manual i.e. both hands used in tasks	Use		For unilateral or Bilateral CP
							Quality	Amount	
HAI Hand Assessment for Infants	Actual Performance	Identifies and measures general manual development and possible upper limb asymmetry in infants at risk of developing cerebral palsy. (Video Mandatory) (Formal Training required)	3m - 12m	10 - 15 mins	20 - 40 mins	Unimanual Bimanual	Y	Y	Unilateral Bilateral
AHA Assisting Hand Assessment	Actual Performance	Assesses performance of the affected hand in bimanual tasks (Video mandatory) (Formal training required)	Mini-AHA 8m - 18m AHA 18m - 12y Ad-AHA 13y +	15 mins	30 - 45 mins	Bimanual only	Y	N	Unilateral
ABILHAND-Kids	Perceived Performance	Paper Questionnaire measures parental perception of a child's performance of manual ability in children aged with cerebral palsy (online scoring)	6y - 15 y	5 mins	5 mins	Unimanual Bimanual	N	N	Unilateral Bilateral
CHEQ Children's Hand Use Experience Questionnaire	Perceived Performance	Online questionnaire Evaluates parental perception or self-reported (13y+) experience of children & young people in using the affected hand in commonly performed bimanual activities.	6y - 18 y	10 - 15 mins	0	Unimanual Bimanual	N	N	Unilateral

Assessment	Assessment Category	Description	Age	Time to Administer	Time to Score	Unimanual i.e. just one hand used in tasks Bi manual i.e. both hands used in tasks	Use		For unilateral or Bilateral CP
							Quality	Amount	
Mini-CHEQ Children's Hand Use Experience Questionnaire	Perceived Performance	Online Questionnaire Evaluates parental perception of their child in using the affected hand in commonly performed bimanual activities.	3y - 8 y	10 - 15 mins	0	Unimanual Bimanual	N	N	Unilateral
COPM Canadian Occupational Performance Measure	Perceived Performance	Structured interview Identifies issues of personal importance to the child and detects changes in the <i>child's self-perception</i> of occupational performance over time or <i>parental perception</i> of the child's occupational performance over time.	0+	Variable - c.30 mins	5 mins	Unimanual Bimanual	N	N	Unilateral Bilateral
GAS Goal Attainment Scaling	Perceived Performance	Measures the extent to which a child's individual goals are achieved in the course of intervention. It involves defining a set of unique goals, and specifying a range of outcomes for concrete activities.	0+	Variable - c.30 mins	10 mins	Unimanual Bimanual	N	N	Unilateral Bilateral
pMAL Pediatric Motor Activity Log	Perceived Performance	Measures change in parents' perceptions of how often and how well children with UCP use their affected arm in everyday activities.	2+	30 mins	?	Unimanual Bimanual	Y	Y	Unilateral Bilateral
HUH (Hand-Use-at-Home questionnaire)	Perceived Performance	Questionnaire – parent report of child's spontaneous use of affected arm – 18 bimanual activities scored using a 5-category rating scale.	3y-10y	?	?	Unimanual	N	Y	Unimanual

Assessment	Assessment Category	Description	Age	Time to Administer	Time to Score	Unimanual i.e. just one hand used in tasks Bi manual i.e. both hands used in tasks	Use		For unilateral or Bilateral CP
							Quality	Amount	
Box & Blocks Test	Capacity	Measures unilateral gross manual dexterity	6y & up	2 - 5 mins	0	Unimanual only	N	N	Unilateral Not specified
JTHFT Jebsen-Taylor Hand Function Test	Capacity	Evaluates functional hand motor skills	Designed for adults but is used with children	15 - 45 mins	10 mins	Unimanual only	N	N	Not specified
MA2 Melbourne Assessment of Unilateral Upper Limb Function 2	Capacity	Evaluates quality of upper limb movement of assessed UL in unimanual tasks (Video mandatory) (Web-based training recommended)	2.5y - 15y	10 - 30 mins	20 - 30 mins	Unimanual only	Y	N	Unilateral Bilateral
QUEST Quality of Upper Extremity Skills Test	Capacity	Evaluates movement patterns and hand function in children with spastic cerebral palsy	18m - 8y	45 mins combined		Observation - no specific assessed UL component	N	N	Unilateral Bilateral
SHUEE Shriners Hospitals Upper Extremity Evaluation	Capacity	Assesses upper extremity functioning in children with UCP (DVD available as illustration)	3y – 18y	15 mins	30 mins	Unimanual Bimanual	N	Y	Unilateral Bilateral

Role of regional clinic:

- Allows critical mass of patients for clinicians to understand clinical phenotypes of children with hemiplegia and have expertise in current literature and evidence for which interventions may be beneficial to each child.
- Linked to research activity to collaborate and recruit to clinical trials.
- To provide a clinical network of support for education and training of local teams
- Children (and their families and siblings) can meet each other at the regional clinic and recognize that there are others with similar difficulties – some may have never met another child with hemiplegia. Often they feel they are a missed group – their impairment is “not severe enough” for local services - “it’s only hemiplegia”
- Can support by providing detailed information to contribute to EHCP in conjunction with the medical report by community team. Increasing pressure on all local and regional services – exacerbates resource issues for these children – regional communication and network can produce educational materials for parent/carer delivered support for everyday activities.

Text Box 1: Co-ordination and delivery of Care: Role of the regional clinic

Hemihelp: www.hemihelp.org.uk

Fun n Games: www.research.ncl.ac.uk/hemiplegiaresearch-fungames

Contact a Family: www.contact.org.uk

CP Sport: www.cpsport.org

SCOPE: www.scope.org.uk

British Paralympics Association www.parasport.org.uk

English Federation of Disability Sport www.efds.co.uk

REMAP: www.remap.org.uk

“The Hemiplegia Handbook” by Liz Barnes and Charlie Fairhurst. 2012. ISBN: 978-1-907-65575-3

Text box 2: Useful resources and websites for information

Self-Assessment Questions

- 1) A two year old is referred to your clinic with delayed motor milestones: she did not walk until age 22 months. The following clinical features would be consistent with a diagnosis of UCP.
 - a. A history of being right hand dominant since age three months.
 - b. Brisk reflexes in all four limbs with extensor plantar responses bilaterally.
 - c. Flexion of the left elbow and wrist and pronation of the forearm when observed walking into the clinic room.
 - d. Frequently bumping into objects, particularly on the left side.
 - e. Wearing out the sole of her left shoe under the toes.
- 2) Which of the following neurological signs can be identified in UCP?
 - a. Dystonia
 - b. Weakness
 - c. Spasticity
 - d. Mirror movements
 - e. Dyskinesia
- 3) Which of the following investigations are required to make a diagnosis of UCP?
 - a. MRI scan
 - b. EEG
 - c. CT scan
 - d. ECG
 - e. None of the above
- 4) Which of the following statements are true?
 - a. The function of the dominant hand is always normal in children with UCP.
 - b. The presence of mirror movements is often due to maintenance of the ipsilateral CST projection from the undamaged hemisphere.
 - c. It is recommended that children with UCP should have a visual assessment, including visual fields.
 - d. The Assisting Hand Assessment assesses capacity of the most affected limb.
 - e. The SHUEE assessment assesses performance of the most affected limb.
- 5) A thirteen year old boy with UCP is struggling at mainstream secondary school. Which of the following recommendations are appropriate?
 - a. Tell him he must wear his resting splint at all times to improve his arm function.
 - b. Recommend detailed neuropsychological cognitive assessment, even though his IQ is reported to be within the normal range.
 - c. Ask about bullying, and sensitively explore any self-esteem issues.
 - d. Discuss technology support options (e.g. use of a tablet or keyboard for written work).
 - e. Consider referral to occupational therapy for school assessment (or check if already referred)

Answers:

- 1) A,C,D,E
- 2) A,B,C,D,E
- 3) E
- 4) B,C
- 5) B,C,D,E