Effective use of the assisting hand in adolescents with cerebral palsy

Louwers, A.M.

Creative Commons License (see https://creativecommons.org/use-remix/cc-licenses):
Other

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

UvA-DARE is a service provided by the library of the University of Amsterdam (http://dare.uva.nl)
Effects of upper extremity surgery on manual performance in children and adolescents with cerebral palsy: a multidisciplinary approach using shared-decision making

Annoek louwers
Jessica Warnink-Kavelaars
Miryam Obdeijn
Mick Kreulen
Frans Nollet
Anita Beelen

Submitted
Abstract

Background

Little is known about the effects of upper extremity surgery (UES) on the manual performance of children and adolescents with cerebral palsy (CP). This clinical cohort study describes our experience with patient selection based on multidisciplinary assessment and shared decision-making (SDM) and the effects of UES on manual performance and patient-relevant outcomes.

Methods

All patients (up to 20 years of age) with CP referred to our multidisciplinary team for UES evaluation between July 2011 to May 2017 were included. Suitability for UES was assessed based on a comprehensive, multidisciplinary screening and the decision to proceed with surgery was made together with the patient. Individual patient-relevant goals were identified with the Canadian Occupational Performance Measure (COPM); perceived independence in performing bimanual activities at home was assessed with the ABILHAND (-kids), and perceived quality of use of the affected hand during daily activities was assessed with a Visual Analog scale (VAS). The quality of use of the affected hand during bimanual performance was measured with the Assisting Hand Assessment (AHA) and gross manual dexterity with the Box and Block Test (BBT). All baseline assessments were repeated 9 months after-surgery.

Results

Of 66 patients assessed by the multidisciplinary UES team, 44 were considered eligible for UES. Of these patients, 39 underwent UES and were evaluated in the pre-post study (mean age 14y9m [SD 2y10m], 87% unilateral CP, 72% MACS level II). All outcomes improved significantly after UES: COPM-Performance +3.2 (SD 1.6) (p<0.001), COPM-Satisfaction +3.3 (SD 2.1) (p<0.001), ABILHAND + 1.5 (SD 1.2) logits (p<0.001), AHA +6.7 (SD 4.2) units (p<0.001), and BBT +2.3 blocks/minute (SD 4.9) (p=0.021). The improvement in COPM-P, COPM-S, ABILHAND, AHA, and BBT performance was clinically meaningful in 80%, 77%, 55%, 71%, and 31% of patients, respectively.

Conclusion

Careful assessment of eligibility for UES, based on multidisciplinary screening and SDM, resulted in a clinically relevant improvement in patient-specific functional and/or cosmetic goals and manual performance after UES in most patients with CP.
Introduction

Spastic cerebral palsy (CP) results in typical disabling deformities of the upper limb and abnormal hand posture that affect the ability to grasp and release objects and to use both hands together. Affected individuals often need assistance to perform everyday activities. Different surgical and nonsurgical interventions are available to improve the ability to use the affected hand effectively during daily activities. Yet their effectiveness is not clear because studies have involved heterogeneous patient populations, few or no patient-relevant outcomes, and ambiguous selection criteria for surgical treatment.

The aim of upper extremity surgery (UES) is to improve muscle balance and hand posture in order to facilitate the ability to grasp, release, and handle objects by: (a) weakening overactive spastic muscles, (b) strengthening weak muscles, and (c) stabilizing unstable joints. The most common procedures for this are: (I) release of pronator teres muscle to facilitate forearm supination, (II) release or transfer of the flexor carpi ulnaris tendon to increase wrist extension for functional grip purposes, (III) correction of a thumb-in-palm deformity, preferably and if possible by adductor pollicis muscle slide combined with extensor pollicis longus rerouting.

Most studies have assessed UES outcomes using a functional classification scale (for example the “House functional classification” and/or instruments assessing wrist/thumb positioning, muscle strength, range of motion, and selective motor control. However, improved functions has not been shown to be associated with a higher ability to perform daily activities. In order to provide patients and professionals with relevant information to enable them to understand the risks, benefits, and outcomes of the various treatment options, more needs to be known about the pros and cons of UES and whether surgery improves the ability to handle objects and perform patient-relevant everyday activities. Appropriate patient selection is important and is preferably done by a multidisciplinary team of professionals and with shared-decision making (SDM). A SDM approach will help the patient and UES team use evidence-based information to come to the best possible treatment decision. This approach encourages patients to express their values and preferences.

This clinical cohort study describes our experience with patient selection for UES, based on a multidisciplinary assessment and SDM, and the effects of UES on manual performance and patient-relevant outcomes in a consecutive series of children and adolescents with unilateral CP.

Methods

Multidisciplinary approach and shared decision-making

The clinical cohort study was performed in a tertiary referral center for UES for patients with CP in the Netherlands and included all patients (up to 20 years of age) with CP who were consecutively referred to our UES team for UES consideration between July 2011 and May 2017. The multidisciplinary UES team consisted of a hand surgeon, pediatric rehabilitation physician and occupational therapist. Each patient was assessed and discussed by the UES team during a single visit in order to reach a shared-decision about whether or not to proceed with surgery.
First, the occupational therapist collected information about patient-specific goals, perceived independence to execute bimanual activities at home, perceived quality of use of the affected hand during daily activities, spontaneous use of both hands, and gross manual dexterity. Then the patients were seen by the hand surgeon and pediatric rehabilitation physician for a medical examination, which included assessment of active and passive range of motion, grip and pinch strength, voluntary and selective motor control, spasticity, and the presence of involuntary movements. To make the best possible treatment decision, the following criteria were assessed and discussed with the patient and their parents (Fig. 1): (I) absence of dystonia or athetosis, because in these types of movement disorders the imbalance of muscles is variable and the outcome of surgery is unpredictable; (II) achievable patient-specified goals (functional and/or cosmetic); and (III) absence of developmental disregard, i.e. a large discrepancy between the ability to use and the actual use of the affected hand.¹⁹,²⁰ The UES team helped the patient compare treatment options and expected outcomes and reached a shared decision with the patient. If UES was not indicated because criterion II or III was not met, alternative conservative treatment options were discussed with the patient, with the possibility for future re-assessment by the UES team.

Assessment of activity limitations

Patients were asked to set five patient-specific “hand-use oriented” goals based on the problems they identified on the Canadian Occupational Performance Measure (COPM) and rated their performance and satisfaction on a scale from 1 to 10 ²¹⁻²⁴, with a minimum clinically important difference [MCID] of >2.²⁵ The perceived independence in performing bimanual activities at home was assessed using the patient/parent-reported questionnaire of unilateral and bilateral activities, ABILHAND(-kids).²⁶,²⁷ In this study, we considered the smallest detectable change of 1.18 logits to reflect a moderate clinically significant change.²⁸,²⁹ The self-perceived “ease of use” of the affected hand when performing daily activities was scored on a visual analog scale (0–10 cm) of 0 to 10). The VAS is sensitive for measuring changes associated with treatment or time and has a MCID of 1.37 cm.³⁰

The quality of use of the affected hand during bimanual performance was measured using the Assisting Hand Assessment (AHA). Object-related hand actions were scored during a semi-structured test situation that elicits the use of both hands. Two different age-related test activities were used to score the AHA 5.0 ³¹, namely, the ‘School-Kids AHA’ and ‘Ad-AHA Board Game’.³²,³³ A score change of 5 AHA units or more (with 95% certainty) reflects a real change exceeding any random measurement error.³³,³⁴ The ability to use the affected hand was assessed with the Box and Block Test (BBT), in which the patient is asked to transfer, with the affected hand, as many blocks as possible from one box to another in 60 seconds.³⁵,³⁶ A change exceeding at least 6 blocks/minute (measured by the same rater) can be interpreted as a true change (with 95% certainty)³⁷,³⁸

Manual performance was categorized using the Manual Ability Classification System (MACS).³⁹
**Figure 1.** Decision-tree for upper extremity surgery (UES) in patients with cerebral palsy, based on multidisciplinary assessment and shared decision-making (SDM)

**Intervention and postoperative therapy**

Different UES procedures were executed (Table 2). After UES, the upper limb was immobilized for 5-6 weeks. After cast removal, day/night resting hand orthoses were used in conjunction with therapy to maintain the increase in muscle length achieved with UES and to facilitate improved motor control. The postoperative therapy was supervised by the patient’s own rehabilitation physician and therapist. All baseline assessments were repeated 9 months after surgery.

**Statistical Analyses**

Paired samples t-tests were performed to compare pre- and postoperative scores on all measures. The level of significance was set at 5% (P<0.05). All analyses were performed with SPSS software, version 21.0 (IBM Corp., Armonk, NY, USA).
Ethics

Before study entry, all patients (>12 years of age) and/or their primary caregivers gave informed consent for the use of their medical data. Participation was voluntary, and all participants were informed that they could withdraw from the study at any stage. The Medical Ethics Committee of our hospital waived the need for ethical approval, because all assessments and interventions were an integral part of standard care.

Figure 2. Flow diagram for assessment of patients with cerebral palsy (CP) eligible for upper extremity surgery (UES)

Results

Between July 2011 and May 2017, 66 patients with CP were consecutively referred to our multidisciplinary UES team, 44 of whom decided to undergo UES (Fig. 2). The results of 5 patients were not available at the time of the study, so the data of 39 patients were used. They were examined on average, 4 months (range 0 - 15 months) before surgery and 9 months (range 6 - 11 months) after surgery. The age of the included patients ranged between 7 years 10 months and 19 years 7 months. Twenty-two patients were not selected for UES after multidisciplinary assessment and SDM, 2 of whom preferred a non-surgical intervention despite being considered eligible for UES by the UES team (Table 1).

Eligibility for UES was based on the extensive multidisciplinary assessment. The COPM identified patient-specific “hand-use oriented” goal(s), which were linked to the different surgical procedures (Table 2). Information from the Abilhand, AHA, and BBT was considered to obtain insight into the ability to use the affected hand and the likelihood that COPM goals could be achieved. For example, the goal of one of the adolescents was to be
able to move and position coins with the affected hand without the help of the other hand. The UES team explained that the patient probably would not be able to achieve this goal because the pre-surgery score on the AHA showed that the affected hand could function as assisting hand but would not be able to stabilize objects effectively. This complex movement requires the independent movement of fingers, which would not be achieved with UES. Together with the UES team, the patient refined his/her goals and expectations. The UES team advised 8 patients to start preoperative therapy in order to stimulate the actual use of the hand during daily activities. This advice was given to 2 patients because there was a discrepancy between the actual use of the affected hand (measured by the Abilhand and AHA) and the ability to use the affected hand (measured by the BBT), and to 6 patients because alternative, non-surgical treatments had not been tried previously (Fig. 2).

Table 3 presents the mean differences between pre-and postoperative assessments and the proportion of patients achieving clinically meaningful improvement in the self-reported outcomes (COPM, ABILHAND, and VAS), unimanual capacity (BBT), and in the case of unilateral CP in manual performance (AHA). All outcomes showed a statistically significant improvement at 9 months. 80% and 77% of the participants had a clinically significant improvement in COPM performance and satisfaction, respectively and 71% on manual performance (AHA) (Table 3). Patients whose primary goal was to improve the appearance of the affected upper extremity also showed improved manual performance and patient-specific functional goals (Table 4).

Table 1. Characteristics of all 66 children/adolescents with cerebral palsy assessed for upper extremity surgery (UES)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>No-UES indicated</th>
<th>No-UES indicated (yet)</th>
<th>No-UES Patient-decision</th>
<th>UES indicated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>5</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age</td>
<td>15y4m</td>
<td>13y1m</td>
<td>16y1m</td>
<td></td>
</tr>
<tr>
<td>Bilateral</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unilateral</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affected side</td>
<td>Left</td>
<td>6</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Right</td>
<td>3</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>Spastic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dysskinetic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MACS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>missing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 3 presents the mean differences between pre-and postoperative assessments and the proportion of patients achieving clinically meaningful improvement in the self-reported outcomes (COPM, ABILHAND, and VAS), unimanual capacity (BBT), and in the case of unilateral CP in manual performance (AHA). All outcomes showed a statistically significant improvement at 9 months. 80% and 77% of the participants had a clinically significant improvement in COPM performance and satisfaction, respectively and 71% on manual performance (AHA) (Table 3). Patients whose primary goal was to improve the appearance of the affected upper extremity also showed improved manual performance and patient-specific functional goals (Table 4).
## Table 2. Patient-specific “hand-use oriented” goals linked to the surgical options

<table>
<thead>
<tr>
<th>Examples of patient-specific “hand-use oriented” goals</th>
<th>To facilitate:</th>
<th>Type of surgery performed</th>
<th>No of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Combing long hair</td>
<td>Elbow extension</td>
<td>Z-lengthening of the biceps tendon and/or brachialis muscle slide(^{22})</td>
<td>2</td>
</tr>
<tr>
<td>Washing oneself (in the shower)</td>
<td>Forearm supination</td>
<td>Pronator teres release(^{23,24})</td>
<td>14</td>
</tr>
<tr>
<td>Holding a plate</td>
<td>Wrist extension</td>
<td>Release or transfer of the FCU tendon(^{25})</td>
<td>30</td>
</tr>
<tr>
<td>Making the bed</td>
<td>Thumb abduction and opposition</td>
<td>Adductor pollicis muscle slide(^{26}) combined with an EPL rerouting(^{27}) (correction of a thumb-in-palm deformity)</td>
<td>30</td>
</tr>
<tr>
<td>Carrying a box (with 2 hands)</td>
<td>Finger extension (while wrist is extended)</td>
<td>Fractional lengthening of the extrinsic finger flexor muscles</td>
<td>8</td>
</tr>
<tr>
<td>Holding paper while writing</td>
<td>Joint stabilization of thumb MCP</td>
<td>Capsulodesis procedure thumb MCP(^{28}) (by hyperextension)</td>
<td>13</td>
</tr>
<tr>
<td>Washing and drying dishes</td>
<td>Stabilization of the fingers</td>
<td>Stabilization of Swanneck deformities in the fingers(^{29})</td>
<td>10</td>
</tr>
<tr>
<td>Holding game controller</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table 3. Performance on different measures of outcome pre-intervention and 9 months post-intervention

<table>
<thead>
<tr>
<th>Measure</th>
<th>N</th>
<th>Pre-intervention</th>
<th>Post-intervention 9-month</th>
<th>∆ Mean difference (SD)</th>
<th>P-Value</th>
<th>Clinically meaningful improvement (% of the participants)</th>
<th>Above smallest detectable change (% of the participants)</th>
</tr>
</thead>
<tbody>
<tr>
<td>COPM-P (SD)</td>
<td>35</td>
<td>3.4 (1.3)</td>
<td>6.5 (1.7)</td>
<td>3.2 (1.6)</td>
<td>&lt;0.001</td>
<td>80%</td>
<td></td>
</tr>
<tr>
<td>COPM-S (SD)</td>
<td>35</td>
<td>3.5 (1.7)</td>
<td>6.6 (1.7)</td>
<td>3.1 (2.1)</td>
<td>&lt;0.001</td>
<td>77%</td>
<td></td>
</tr>
<tr>
<td>ABILHAND-logits (SD)</td>
<td>34</td>
<td>0.9 (1.9)</td>
<td>2.4 (1.8)</td>
<td>1.5 (1.2)</td>
<td>&lt;0.001</td>
<td>55%</td>
<td></td>
</tr>
<tr>
<td>VAS (SD)</td>
<td>29</td>
<td>3.3 (2.0)</td>
<td>5.7 (1.9)</td>
<td>2.4 (1.9)</td>
<td>&lt;0.001</td>
<td>62%</td>
<td></td>
</tr>
<tr>
<td>AHA-units (SD)</td>
<td>31</td>
<td>49.7 (10.9)</td>
<td>56.4 (11.2)</td>
<td>6.7 (4.2)</td>
<td>&lt;0.001</td>
<td>71%</td>
<td></td>
</tr>
<tr>
<td>BBT (SD)</td>
<td>29</td>
<td>19.8 (9.9)</td>
<td>22.1 (10.4)</td>
<td>2.3 (4.9)</td>
<td>0.021</td>
<td>31%</td>
<td></td>
</tr>
</tbody>
</table>

SD=standard deviation; COPM-P: Canadian Occupational Performance Measure (COPM) performance, COPM-S: Canadian Occupational Performance Measure (COPM) satisfaction, VAS: Visual Analog scale, AHA; Assisting Hand Assessment, BBT: Box and Block Test

### Table 4. Patient-specific functional and cosmetic goals

<table>
<thead>
<tr>
<th>Order of importance to participant</th>
<th>MACS level</th>
<th>Clinically meaningful improvement n (%) of the participants</th>
<th>Satisfied about cosmetic result</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n I II III</td>
<td>COPM-P COPM-S BBT AHA ABILHAND VAS</td>
<td></td>
</tr>
<tr>
<td>1. Functional goals</td>
<td>15 0 10 5</td>
<td>10 10 5 10 9 5</td>
<td>77% 77% 39% 77% 69% 39%</td>
</tr>
<tr>
<td>2. no cosmetic goal</td>
<td>15 0 10 5</td>
<td>10 10 5 10 9 5</td>
<td>77% 77% 39% 77% 69% 39%</td>
</tr>
<tr>
<td>1. Functional goals</td>
<td>14 1 10 3</td>
<td>8 8 1 4 2 4</td>
<td>89% 89% 11% 44% 22% 44%</td>
</tr>
<tr>
<td>2. Cosmetic goal</td>
<td>14 1 10 3</td>
<td>8 8 1 4 2 4</td>
<td>89% 89% 11% 44% 22% 44%</td>
</tr>
<tr>
<td>1. Cosmetic goal</td>
<td>8 1 7 0</td>
<td>6 6 2 7 4 4</td>
<td>86% 86% 29% 100% 57% 57%</td>
</tr>
<tr>
<td>2. Functional goals</td>
<td>8 1 7 0</td>
<td>6 6 2 7 4 4</td>
<td>86% 86% 29% 100% 57% 57%</td>
</tr>
</tbody>
</table>
Chapter 6

Discussion

The present study shows that a multidisciplinary approach using SDM to select patients likely to benefit from UES resulted in clinically relevant improvements in manual performance and patient-relevant outcomes after UES in more than 80% of the assessed children and adolescents with CP. Thus this approach appears to be effective in selecting patients who may benefit from upper extremity surgery.

The comprehensive multidisciplinary assessment and strict selection criteria contributed to the effectiveness of surgery in this patient population (87% unilateral spastic CP, 72% MACS level II), based on the improvement in manual performance. Given the high proportion of successful outcomes, it can be questioned whether our selection criteria for UES were too strict and more patients might benefit from surgery. For instance, manual performance may also improve after UES in patients with a low ability to handle objects (MACS level III, IV) or only a few limitations (MACS level I). In particular, patients with MACS level III or IV may benefit from the improved muscle balance and more normal hand posture achieved with UES, followed by rehabilitation interventions, such as intensive bimanual training. Even small changes in muscle balance may change a non-functional hand into a hand that is able to hold objects passively or stabilize objects, as measured with the AHA.31,33

In the current study, as most patients showed a clinically significant improvement, it was not possible to refine selection criteria based on the characteristics of patients who did not show such improvement. Future research should evaluate whether adapting the UES selection criteria leads to improvement across all MACS levels.

Although it was not possible to distinguish the specific effects of SDM on UES outcomes, this study showed that involving patients in treatment decisions was beneficial. This enabled the UES team to align surgical and postoperative treatment plans and to achieve the best outcome in terms of patient-specific goals. Only two patients preferred nonsurgical treatment. In both cases, the choice was based on a lack of motivation for the intensive postoperative rehabilitation. Prior to UES, the feasibility of achieving patient-specific goals was carefully discussed, so that patients had clear and realistic expectations about what could be achieved, which resulted in a high level of satisfaction with the functional and cosmetic outcomes. Our findings show that selection of the appropriate procedure is linked to the achievement of patient-relevant goals.

A high proportion of patients achieved clinically meaningful improvements in self-reported outcomes (COPM, ABILHAND and VAS), unimanual capacity (BBT), and in the case of unilateral CP in manual performance (AHA). However, it should be appreciated that results for different outcome measures may vary, because of differences in patient-specific goals, choice of surgical procedure, and manual performance before surgery. For example, while manual performance did not improve in some patients, these patients experienced that they could use the affected hand more effectively in terms of their patient-relevant outcomes and vice versa. These findings confirm previous evidence that the evaluation of UES should be based on different outcomes.16,17 The instruments used in this study measured different constructs and were complementary, which makes them suitable for selecting patients eligible for UES and for evaluating the effect of surgery.

In our study, 59% of the patients (22 out of 37) had a cosmetic goal for UES, such as “hope my hand looks more normal and/or less noticeably different”, no flexed wrist, thumb out of the palm, and correction of Swanneck finger deformities. These patients were embarrassed by the appearance of the spastic hand and often used to hide their hand
behind the back, in pockets, or under the table, with as consequence that the affected hand was not used to perform daily activities. This might explain why, in this study, all patients who were pleased with the cosmetic appearance of their hands after surgery also showed improved manual performance and patient-specific functional goals. This is one of the reasons it is important not to underestimate the psychosocial impact of a hand deformity and the effect on manual performance.

On the basis of these findings, it would be advisable to use a core set of instruments to assess the effect of UES, to predict outcomes, and to improve selection criteria. Use of a standard set of instruments would also make it easier to compare the results of different studies. In addition to the instruments used in this study (COPM, AHA, ABILHAND and BBT), a validated instrument measuring patient satisfaction with cosmetic appearance will add important information to the patient-specific goals. A limitation of this study is that instruments that could link function and activity were not used. Therefore, as a last addition, the “Shriners Hospitals Upper Extremity Evaluation” dynamic positional analysis (SHUEE-DPA) should also be included. The SHUEE-DPA analyzes body function (in five different segments: thumb, finger, wrist, forearm, and elbow) by describing the position of the segment during 16 different activities. This would make it possible to measure and link “function” and “activity” when evaluating the result of UES.

A limitation of this study is its observational design and lack of control group when evaluating the effect of UES. Although a randomized controlled trial (RCT) is the best trial design for determining treatment effectiveness, different factors, such as the permanence and invasive character of the surgery and patient preferences, may limit the feasibility of RCTs in children and adolescents. Only a few trials of varying quality have reported the effect of UES on manual performance. Instead of RCTs, sound observational studies may be the next best method to evaluate the effect of UES. “Real-life” studies may help intervention planning, by describing the selection process, the personalized intervention, and patient-relevant outcomes. Additional high-quality observational studies of the effectiveness of UES are needed. Another limitation of this study was that different pediatric rehabilitation physician and therapists carried out the intensive postoperative functional program and its content was not monitored. A standardized postoperative hand therapy program that can be customized to patient-specific goals is needed in order to optimize the outcome of UES. Because of the small number and heterogeneous characteristics of the children and adolescents with CP referred to each UES team, preference should be given to a multicentre study. With a larger study, preferably a randomized controlled trial with a waiting-list control group and a longer follow-up, it should be possible to define patient selection criteria (based on e.g. age, severity) and to predict and achieve optimal outcomes that match patient-specific goals and expectations.

Conclusions
This study showed that careful patient selection, based on multidisciplinary assessment and SDM, results in clinically relevant improvements in patient-specific functional and/or cosmetic goals and manual performance after UES in children and adolescents with CP.
Acknowledgments

We particularly thank the children and adolescents and their caregivers referred to the Department of Rehabilitation (Academic Medical Centre, Amsterdam, the Netherlands) who provided data for the analyses. We gratefully acknowledge financial support from Stichting Rotterdams Kinderrevalidatie Fonds Adriaanstichting and Johanna KinderFonds (The Netherlands).

References


34. Krumlinde-Sundholm L, Reporting outcomes of the Assisting Hand Assessment: what scale should be used? Developmental Medicine & Child Neurology. 2012. 54(9), 807-808.


43. Van Heest AE, Bagley A, Molitor F, James MA. Tendon transfer surgery in upper-extremity cerebral palsy is more effective than botulinum toxin injections or regular, ongoing therapy. JBJS. 2015. 97(7), 529-536.