Goal-Directed Personalized Upper Limb Intensive Therapy (PULIT) for Children With Hemiparesis: A Retrospective Analysis

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Importance: Children with hemiparesis experience limitations in activities of daily living (ADLs) as a result of upper limb impairments. To address these limitations, we developed a group-based Personalized Upper Limb Intensive Therapy (PULIT) program combining modified constraint-induced movement therapy, bimanual intensive therapy, and exergame-based robotics.

Objective: To determine the effectiveness of PULIT in helping children with upper limb impairments achieve individually set goals and enable transfer of the attained motor skills into ADLs.

Design: Retrospective analysis.

Setting: Day camp at a pediatric rehabilitation clinic in Switzerland.

Participants: Twenty-three children with upper limb impairment (unilateral cerebral palsy, $n = 16$; acquired brain injury, $n = 7$); 13 boys and 10 girls (M age = 7 yr, 8 mo, SD = 2 yr, 1 mo; Manual Ability Classification System Level I–IV).

Intervention: Thirty hours of PULIT over the course of 8 days.

Outcomes and Measures: Goal attainment scaling (GAS) was assessed on the first and last day of intervention. The Canadian Occupational Performance Measure (COPM) and dexterity tests, such as the Box and Block Test (BBT), were administered 3 wk before and 3 wk after the intervention.

Results: Total goal achievement was 85.7%. GAS, parent- and child-rated COPM Performance and Satisfaction, and the BBT of the affected and dominant upper limb improved significantly.

Conclusions and Relevance: PULIT effectively increases children's dexterity of the impaired and dominant upper limb, improves ADL performance, and achieves individual goals. This retrospective analysis could serve as a basis for a future randomized trial.

What This Article Adds: This article informs occupational therapy practitioners about a therapy program that includes conventional and rehabilitation technology interventions and enables children with hemiparesis of the upper limb to improve relevant ADL tasks in 8 days' time.

Children diagnosed with congenital or acquired brain lesions often experience upper limb impairments that limit their independence while performing activities of daily living (ADLs). The most frequently investigated interventions to enhance upper limb function in children are modified constraint-induced movement therapy (mCIMT), bimanual intensive therapy (BIT), exergame-based robotics, and robot-assisted training (Shierk et al., 2016). mCIMT involves putting a restraint on the unaffected hand to induce intensive

use of the affected hand during task-oriented therapy (Aarts et al., 2011). In contrast, BIT focuses on improving bimanual coordination of the two hands during repetitive tasks. Both interventions are effective when used with children and adolescents with hemiparesis (Klepper et al., 2017; Simon-Martinez et al., 2018). The required number of movement repetitions is challenging to achieve, especially among children, and thus motivation is a critical factor.

Robots, in combination with exergames, can provide high-dose and high-intensity training with precise feedback on movement accuracy and induce motor learning in children diagnosed with cerebral palsy (CP; Bertani et al., 2017; Chen et al., 2018; Gilliaux et al., 2015). Motivation can also be enhanced by basing an intervention on the child's personal goals and needs. Goal-directed therapy augments performance and is effective in increasing self-care (Novak et al., 2013). Rehabilitation goals are preferably defined in the domain of activities and participation according to the *International Classification of Functioning, Disability and Health: Child and Youth Version* (World Health Organization, 2007). The combined use of the Canadian Occupational Performance Measure (COPM; Carswell et al., 2004) and goal attainment scaling (GAS) can evaluate different but complementary pieces of information about goal achievement (Willis et al., 2018). Both measurements are responsive in detecting clinically significant change and show good reliability and validity (Sakzewski et al., 2007). Moreover, group-based therapy has been proven to increase engagement and motivation and has demonstrated a positive peer effect on participating children (Eliasson et al., 2003; Simon-Martinez et al., 2018).

To our knowledge, this retrospective analysis is the first to explore the effects of the Personalized Upper Limb Intensive Therapy (PULIT) program, which combines the benefits of mCIMT, BIT, and exergame-based robotics in an individualized goal-directed manner during a themed 8-day camp. We hypothesized that this program would lead to achievement of individually set goals and enable transfer of the attained motor skills into ADLs.

Method
Study Design
This was a retrospective cohort study in which we analyzed data obtained from children who attended a clinical day camp (Figure 1).

Participants
Children and caregivers were informed about the clinical day camp during therapy sessions at our center or by an online flyer. Approximately 6 mo before the camp, we evaluated the children's eligibility to participate. Inclusion criteria were congenital or acquired hemiparesis, age 4 to 18 yr, a Manual Ability Classification System (MACS; https://www.macs.nu/) level of

Figure 1. Timeline of data collection and analysis.
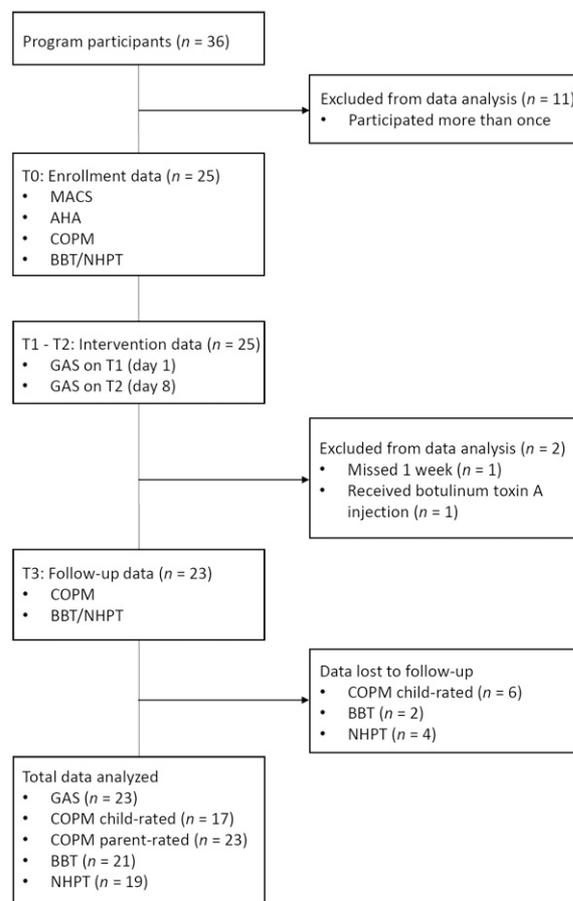
Note. Six children were not able to rate their satisfaction with their performance on the Canadian Occupational Performance Measure (COPM), and four of them were not able to rate their performance. AHA = Assisting Hand Assessment; BBT = Box and Block Test; COPM = Canadian Occupational Performance Measure; GAS = Goal Attainment Scaling, where on Time 1 (T1) goals are set and on Time 2 (T2) the attainment of goals is evaluated; MACS = Manual Ability Classification System; NHPT = Nine-Hole Peg Test; T0 = Time 0.

I to IV, and the ability to flex the shoulder at least 20°. An injection with botulinum toxin A and surgery of the upper limb were not considered exclusion criteria for the clinical program, but they were for the data analysis.

Participants were characterized using the MACS and the Assisting Hand Assessment (AHA; Krumlinde-Sundholm & Eliasson, 2003). The MACS uses a five-level scale to classify a child's ability to handle objects in everyday life, with Level I representing good functioning and Level V denoting significant disability (Eliasson et al., 2006). The AHA consists of 20 items that assess bimanual performance. An occupational therapist observes a child's spontaneous handling of toys in a relaxed and playful session and scores how effectively the affected hand and arm are used in bimanual performance. The therapist uses this assessment to determine the actual level of functionality

of the assisting hand and identify what needs to be trained to achieve higher functioning, for example, a stable grip during bimanual tasks. Occupational therapists grossly evaluated the active and passive range of motion and spasticity of the upper limb joints in each child who participated in this study. In children who showed impairments that could influence therapy planning, therapists assessed the range of motion using a manual goniometer or measured spasticity using the Modified Ashworth Scale (Bohannon & Smith, 1987).

Ethics

Before the camp started, children and their parents were asked permission to use their data for scientific evaluations and publication of the results. Both verbal and signed informed consent were received. The project was approved by the ethics committee of the canton of Zurich, Switzerland (KEK St.V. 24/07), and adhered to Declaration of Helsinki guidelines (World Medical Association, 2008).

Intervention

A group-based day camp model was chosen because such camps have demonstrated a positive peer effect on participating children (Eliasson et al., 2003; Simon-Martinez et al., 2018). The day camp took place at our pediatric rehabilitation center on 4 consecutive half-days for 2 wk. For each PULIT cycle, a playful theme was selected for a group of four children, accompanied by three to four occupational therapists. Each camp was organized so that four children of similar ages could participate. Every day started with 15 min of mCIMT in the group, followed by 60 min of goal-directed BIT in a one-to-one child–therapist setting. If necessary, assisting aids (e.g., pull tabs on zippers to facilitate dressing or undressing or one-handed knots to tie shoes) were adopted individually for each participant. Therapists decided, in line with the Occupational Therapy Intervention Process Model (OTIPM), whether, for example, a better grip needed to be learned, a different strategy practiced, or an assistive aid used (Fisher, 2009). Children then performed exergame-based robotics for 45 min under the guidance of an experienced therapist. The appropriate device and exergame were selected on the basis of the child's sensorimotor impairments, taking into account the individual goals (van Hedel & Aurich, 2016).

Participants trained with devices such as the You-Grabber System (YouRehab, Zurich, Switzerland), the Armeo Spring (Hocoma AG, Volketswil, Switzerland), and Diego and Myro (both from Tyromotion, Graz, Austria). The YouGrabber and Myro provide no physical assistance, but the exergames challenge and motivate participants to train hand, arm, and shoulder movements (van Hedel & Aurich, 2016). The Armeo Spring and Diego are weight-supporting devices that can support the child's upper limb

against gravity and enable training of three-dimensional movements (El-Shamy, 2018). After robotics, 15 min of goal-directed BIT was performed in a group setting. The day ended with 15 min of mCIMT in the group. In total, children practiced 4 hr of mCIMT, 20 hr of BIT, and 6 hr of exer-game-based robotics, and half of the time was spent in group therapy. An example schedule of daily therapy is listed in Table A.1 in the Supplemental Material, available online with this article at https://research.aota.org/ajot.

Outcome Measures

We selected GAS as the primary outcome to measure the effects of the intervention on children's individually negotiated performance. Together with an experienced physical therapist, who was otherwise not involved in the program, goals were defined that should be achievable after 8 days of PULIT. GAS varies between –2, indicating no change in performance compared with baseline; through 0, representing the expected level of outcome (goal achieved); and +2, indicating an exceeded level of outcome (Kiresuk & Sherman, 1968). Participants did not score the importance and difficulty of the goals, as advised by Turner-Stokes (2009), because such ratings are difficult for many people, especially young children.

The subjective rating of achievement and satisfaction with performance using the COPM was included; this was one of the secondary outcomes. During the semistructured COPM interview, both the child and the parent could prioritize up to seven problems each that are relevant to ADLs; these were then rated for performance and satisfaction on a visual analog scale (children made ratings using smiley faces) and converted into a 10-point scale, with 10 indicating the highest level of performance or satisfaction (Cusick et al., 2007). Goals from the child and parent often overlapped, but all goals were included for training.

Further secondary outcomes were the Box and Block Test (BBT) and the Nine-Hole Peg Test (NHPT), to assess the children's unimanual capacity for both hands. The BBT examines the number of cubes a child can move from one side of a box to the other within 1 min. It tests a child's grasping ability and more proximal arm functioning and hence gross manual dexterity (Jongbloed-Pereboom et al., 2013). The NHPT measures the time a child needs to insert and remove nine pegs from nine holes in the pegboard, thus assessing fine manual dexterity (Poole et al., 2005). The secondary outcomes were performed by occupational therapists. Each year, a small team of two to three occupational therapists administered the assessments for these intensive camp weeks. We ensured that, for each participant, the same therapist administered the pre- and postintervention assessments. At the time of scoring, raters were unaware of the initial scores. For the timeline of data collection, see Figure 1.

Data Selection

We retrospectively analyzed data from the children who participated from October 2013 to October 2018. The day camp had taken place annually from 2013 to 2015 and biannually from 2016 to 2018. Of the children who had participated multiple times in the program, only data from the first period were included. Other exclusion criteria for the analysis were not completing the program, receiving an injection of botulinum toxin A 3 mo before or during the intervention, and upper limb surgery up to 6 mo before the intervention.

Statistical Analysis

Statistical analysis was performed using IBM SPSS Statistics (Version 22). Inspection for a normal distribution of interval-scaled data was done using histograms, skewness, kurtosis, and the Shapiro–Wilk test. For each measurement, means and standard deviations or median and interquartile ranges (IQRs) were calculated. We performed pairwise testing with parametric (paired t tests) or nonparametric tests (Wilcoxon signed-rank tests). We analyzed the correlation between participants' characteristics and the outcome measures using bivariate Pearson's r or Spearman's ρ correlation coefficients. Differences between groups were analyzed with a t test, and differences between children's affected and nonaffected sides were analyzed with paired t tests. Ninety-five percent confidence intervals were calculated, and α was set at .05. For multiple comparisons, the α level was adjusted ($\alpha = .0125$ for the COPM and $\alpha = .025$ for the BBT and NHPT). For a normal distribution, Cohen's d was calculated, with ds exceeding 0.2, 0.5, or 0.8 representing a small, medium, or large effect size (ES), respectively (Lenhard & Lenhard, 2016). For data that were not normally distributed, the ES r_{ES} (z score/ $\sqrt{N}$) was calculated, with values exceeding .1, .3, or .5 representing a small, medium, or large ES, respectively (Field, 2009).

Results

Thirty-six children participated in the day camp. The timeline of data collection and analysis is shown in Figure 1. Data from 10 girls and 13 boys were included in the retrospective analysis. Children had a mean age of 7 yr, 8 mo ($SD = 2$ yr, 1 mo), range = 4 yr, 6 mo, to 12 yr, 5 mo. The baseline characteristics are shown in Table 1. The median AHA scaled score was 60% (IQR = 50%–76%), and scores varied from 12% to 79%. Participants diagnosed with acquired brain lesions were in the chronic stage (between 1 yr, 3 mo, and 7 yr, 0 mo, after lesion).

On average, the participants chose 3.4 goals ($SD = 1.2$, range = 1–5 goals per child). Of the 77 GAS goals, 74 were formulated on the level of activity (see Figure 2, Panel A). Most goals related to self-care, in particular, dressing and eating. For example, when the goal was to zip a jacket independently, this included all parts of the

**Table 1.** Participants' Demographic Characteristics

Characteristic	n	I	II	III	IV	V
Gender						
Female	10	1	6	2	1	
Male	13		6	4	3	
Age, yr						
4–7	8		5	3		
7–10	12	1	5	3	3	
10–13	3		2		1	
Total	23	1	12	6	4	0
Etiology of hemiparesis						
Unilateral cerebral palsy	16	1	9	5	1	
Spastic	13	1	7	4	1	
Dyskinetic[a]	1		1			
Ataxic	0					
Mixed[b]	2		1	1		
Acquired hemiparesis	7		3	1	3	
Ischemic stroke	2		1		1	
Hemorrhagic stroke	2				2	
Epilepsy[c]	3		2	1		
Hemiparetic side						
Left	8		5	2	1	
Right	15	1	7	4	3	

Note. $n = 23$. Use of the MACS was extended for use with children with acquired hemiparesis. Level I = good functioning; Level V = significant disability; MACS = Manual Ability Classification System. [a]Athetotic, dystonic, choreic. [b]Mixed spastic and dyskinetic. [c]Consequences of an epileptic disorder (e.g., epileptic surgery or epileptic status).

task (e.g., insert the zipper into the zip slider, pull up the zipper) or, when the goal was to put on shoes, this included getting into the shoes and tying the shoelaces. For a detailed list of the chosen goals, see Table A.2 in the Supplemental Material. After 8 days of PULIT, 66 of the 77 goals (85.7%) were attained (see Figure 2, Panel B). Thirty goals were accomplished at the expected level, and 36 were accomplished at a higher level than expected. Of the 23 children included in the data analysis, 15 reached all of their goals, and 8 reached one or more goals. No participant did not reach any goal. Goal achievement was significant ($p < .001$), with a large ES. Goal achievement did not correlate significantly with age, MACS level, AHA score, time since acquired brain lesion, or number of chosen goals.

During the COPM interviews, children identified 76 goals and prioritized, on average, 3.1 goals ($SD = 2.1$). Parents identified 1 to 10 goals ($M = 4.0$, $SD = 2.0$). COPM ratings of performance and satisfaction were statistically significant and showed large ESs (see Table 2).

Figure 2. Overview of PULIT results.

A

B

Goal Attainment Scaling

C

Canadian Occupational Performance Measure
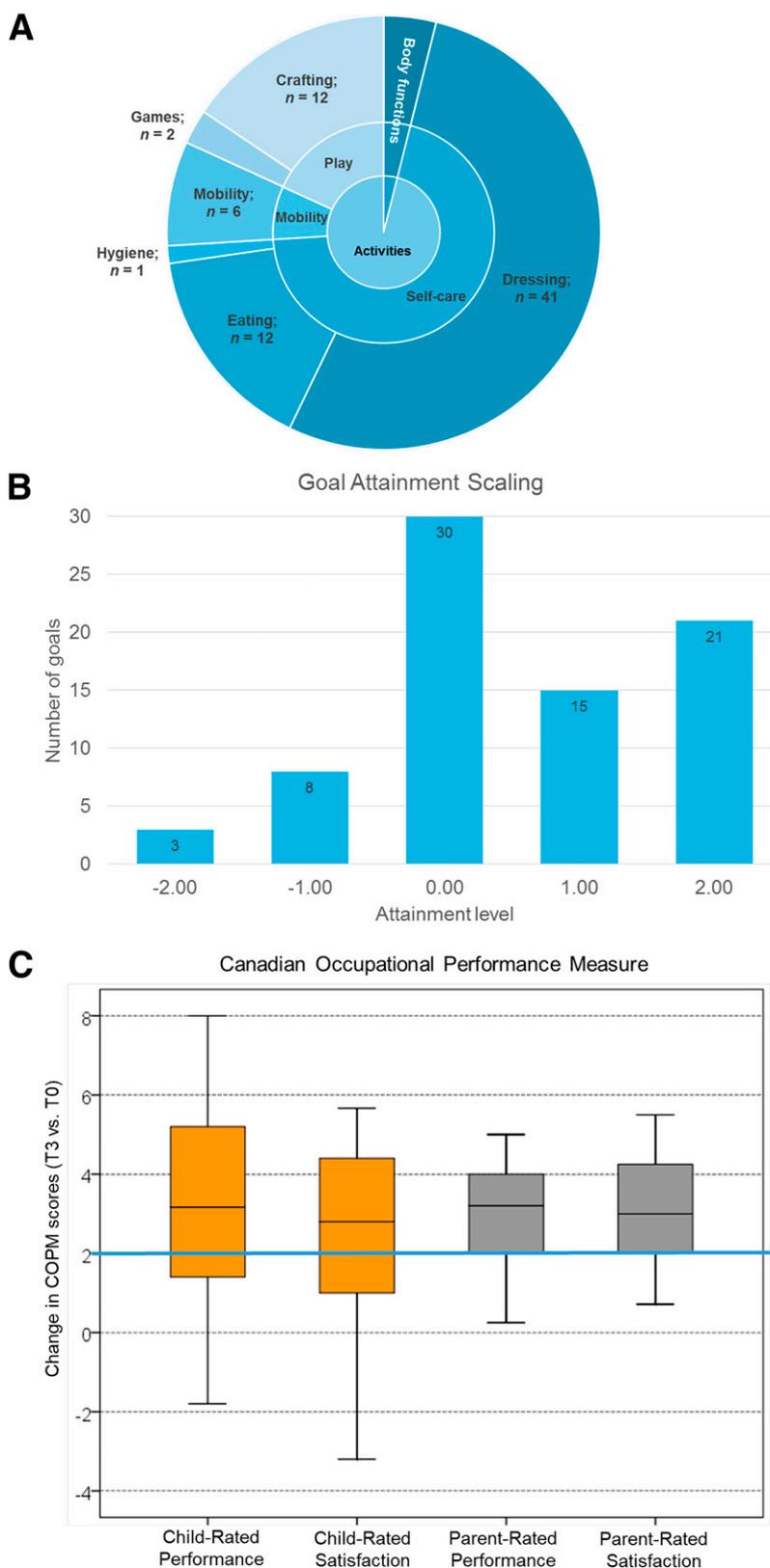
Note. A: Pie chart showing in detail the personalized goals chosen by the participants. B: Frequency of goals per attainment level after 8 days of PULIT. An attainment level <0 represents nonachievement of the set goal. A value of −1 indicates that an improvement was perceived, and −2 corresponds to the baseline level. An attainment level ≥0 indicates goal achievement, 0 corresponds to the expected level after 8 days of intervention, and 1 and 2 indicate an exceeded level. C: Box-and-whisker plot of mean change in scores rated by the children and their parents. The blue line emphasizes a score of 2, representing the minimal clinically important difference. We analyzed COPM change by comparing the differences between scores at Time 0 (T0; 3 wk before intervention) and Time 3 (T3; follow-up at 3 wk after the intervention). COPM = Canadian Occupational Performance Measure; PULIT = Personalized Upper Limb Intensive Therapy.

Table 2. Primary and Secondary Outcomes of PULIT

Outcome Measure	n	T0, M (SD)	Mdn (IQR) T1	Mdn (IQR) T2	T3, M (SD)	p	ES
Primary: GAS	23		−2.00 (0.00)	1.00 (1.00)		<.001*	r_{ES} = .89[a]
Secondary							
Child-rated COPM performance	19	3.62 (1.79)			7.02 (2.21)	<.001**	d = 1.40[a]
Child-rated COPM satisfaction	17	4.98 (2.29)			7.59 (1.72)	.001**	d = 0.94[a]
Parent-rated COPM performance	23	3.64 (1.11)			6.82 (1.58)	<.001**	d = 2.55[a]
Parent-rated COPM satisfaction	23	4.03 (1.74)			7.20 (2.04)	<.001**	d = 2.07[a]
BBT affected side	21	16.48 (9.00)			18.57 (9.13)	.007***	d = 0.67[b]
BBT dominant side	21	49.76 (10.20)			55.05 (10.22)	.001***	d = 0.84[a]
NHPT affected side	19						
Group 1	5	90.10 s (31.98)			82.82 s (25.88)	.579	d = 0.25[c]
Group 2	4	Not possible			148.02 s (41.35)		
Group 3	10	Not possible			Not possible		
NHPT dominant side	19	24.50 s (5.43)			23.16 s (4.26)	.126	d = 0.35[c]

Note. Five children completed the NHPT at both T0 and T3, 4 children were not able to do so at T0 but were able at T3, and 10 children were not able to complete it at T0 or T3. BBT = Box and Block Test; COPM = Canadian Occupational Performance Measure; ES = effect size; GAS = goal attainment scaling; IQR = interquartile range; NHPT = Nine-Hole Peg Test; PULIT = Personalized Upper Limb Intensive Therapy; T0 = Time 0, T1 − 3 wk; T1 = Time 1, Day 1 of intervention; T2 = Time 2, Day 8 of intervention; T3 = Time 3, T2 + 3 wk.
[a]Large. [b]Medium. [c]Small.
*p = .05. **p = .0125. ***p = .025.

All means exceeded the published minimal clinically important difference of 2 points (see Figure 2, Panel C; Carswell et al., 2004). There was no significant correlation between change in COPM score and MACS level, AHA score, time since acquired brain lesion, or number of chosen goals. No significant difference was found in change scores between groups on the basis of gender, diagnosis, or affected side; however, there was a significant negative correlation ($r = −.443$, $p = .034$) between the child's age and the parent's rating of COPM performance.

Gross manual dexterity, quantified with the BBT, improved to a notable extent. Fine manual dexterity was difficult to analyze because only some children were able to perform this test (see Table 2). There was no correlation between changes in BBT or NHPT and age, MACS level, AHA score, or time since acquired brain lesion. In addition, there was no difference between groups on the basis of gender, diagnosis, or affected side.

Discussion

PULIT is a group-based, individualized, and goal-directed combination of mCIMT, BIT, and exergame-based robotics. In this study, we retrospectively analyzed children's PULIT data to investigate whether children with upper limb impairment could reach

goals focused on ADLs after 8 days of participation. Every child reached at least one goal, with a total goal attainment of 85.7%. COPM ratings on performance and satisfaction were significant and showed large ESs. A significant change in BBT performance and a corresponding medium ES showed that children increased their unimanual capacity with the affected limb as well as the dominant upper limb. There was no significant change in NHPT performance, which may be explained by the small number of children who were able to perform the test before and after intervention. Four children were not able to perform the test before the intervention but were able to do so afterward; these children's data could not be analyzed statistically but indicate a clinically relevant improvement.

Previous studies have explained changes in manual dexterity of both upper limbs with the fact that unilateral motor training leads to changes in motor cortex excitability for the trained and nontrained hand (e.g., Grothe et al., 2017; Kuo et al., 2018).

The pragmatic approach of PULIT leads to the inclusion of children with MACS Levels I to IV. A systematic review of therapeutic interventions showed that, in most studies, three-quarters of the included participants have a MACS Level of I or II (Shierk et al., 2016). In this program, children with more severe impairments were included, with only 4.2%

having a MACS Level I and 41.6% with MACS Level III or IV, showing that the results apply also to children with more severe upper limb impairments.

Although the results of the BBT showed that most of the children with MACS Level III or IV improved functionally, part of the improvements in GAS or on the COPM might also be explained by the introduction or adoption of assistive aids, in line with the OTIPM (Fisher, 2009). These therapy adjustments, together with the ability to choose goals important to each participant's daily life, provide a beneficial personalization of PULIT.

Both children diagnosed with CP and those diagnosed with acquired brain injuries were included in this clinical program. Previous insight shows that elaborated training designs for children diagnosed with CP are adaptable for use with children diagnosed with acquired brain injuries (Komar et al., 2016). The clinically significant results for GAS and the COPM in this program are comparable to the results of a randomized controlled trial conducted by Aarts et al. (2010), in which 28 children received a total of 72 hr of combined CIMT and BIT for 8 wk, showing notably larger results than a control group who received usual care. Although children obtained similar results in this program, they did so in half the time, namely 30 hr of therapy compared with 72 hr. This could be explained by the combination of mCIMT and BIT with exergame-based robotics, leading to an amplification of the necessary movements practiced. Gilliaux et al.'s (2015) randomized controlled trial, in which eight children diagnosed with CP received an intervention of 24 hr of conventional and 16 hr of robot-assisted therapy sessions, confirms our explanation. However, Gilliaux et al. did not investigate whether the changes in manual dexterity measured by the BBT could be transferred to improvements in ADLs. To test for this transfer, GAS and the COPM can be used as outcome measures. Willis et al. (2018) were one of the first to evaluate participation as the primary outcome measure for children with upper limb impairments. They postulated that 12 wk of intervention, including different methods of occupational therapy, were inefficient to achieve a 0 on GAS given that only 32% of the participants attained their goals. In this program, however, children received a goal attainment rate of 85.7% after only 8 days of intervention, implying that this method reduces the amount of therapy needed to achieve important goals and transfer them into ADLs.

The results of this retrospective analysis of this program are congruent with those found by Sakzewski et al. (2011), who showed that COPM performance differences were retained for both the CIMT and BIT intervention groups 1 yr after completing an 8-day therapy camp. Although we lack a long-term follow-up, we assume that the children who participated in PULIT will profit in the long term because they were able to improve ADLs, which is considered a prerequisite for long-term maintenance because of daily practice. Despite the fact that improved ADL performance might be caused by both recovery and compensatory strategies, it is likely accompanied by motor cortex plasticity induced during intensive training of the upper limb. Friel et al. (2016) showed that structured bimanual training leads to an increased size of the affected hand's motor map and amplitudes of motor-evoked potentials. These changes in map size correlated with functional improvement on the COPM, whereby the COPM changes were equivalent to the ones in this program.

Limitations

Because this study is the retrospective evaluation of a clinical program, limitations include the lack of a control group and random selection of the participants, which could introduce bias and affect assumptions about the causality of the effects. The results of this analysis should be considered with caution but might serve as a basis for developing new clinical protocols, including those that focus on the PULIT contents or performing sample size calculations for future randomized trials.

Another limitation is that the secondary outcomes were assessed some weeks before and after the intervention. For a future randomized trial, assessments like the BBT and NHPT should be administered directly before and after the intervention. However, the timing of administering the COPM several weeks after finalizing the PULIT camp can be considered valid because some time is needed to observe whether the children actually showed improvement in ADLs.

Implications for Occupational Therapy Practice

The results of this analysis have the following implications for occupational therapy practice:

- The group-based combination of mCIMT, BIT, and exergame-based robotics (PULIT) led to functional improvements in the affected and the dominant upper limbs of children with hemiparesis.
- It is important that the occupational therapist practice goals that are important to the child and the caregiver. Children were able to achieve individually set goals with PULIT in 8 days of therapy.
- Occupational therapists might use PULIT as a booster session for children to learn relevant ADLs.

Conclusion

Thirty hours of PULIT, a group-based combination of mCIMT, BIT, and exergame-based robotics, seems to be an effective means to achieve individualized goals and increase manual dexterity in a heterogeneous group of children with congenital or acquired upper limb impairments. It might be used as a booster session to help children learn important ADLs and

therefore help them gain functional independence. We have shown that PULIT reaches an equal therapy effect in a shorter time period and with fewer hours of training as previous randomized controlled trials using state-of-the-art-therapy for children with (severe) upper limb impairments. ⚕

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