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Effectiveness of functional intensive therapy on mobility and self-care activities in children and adolescents with cerebral palsy - a prospective clinical study

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ORIGINAL ARTICLE

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Effectiveness of functional intensive therapy on mobility and self-care activities in children and adolescents with cerebral palsy – a prospective clinical study

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ABSTRACT

Purpose: Cerebral palsy (CP) is a major cause of childhood disability. Children with CP often lack motor skills to effectively perform activities of daily living. The aim is to assess the effectiveness of a functional intensive therapy program focused on improving individual goals in the domain of mobility and self-care in children and adolescents with CP.

Material and methods: Thirty-five CP patients, aged 11–19 years, GMFCS I–IV, received daily 6–7 h of functional therapy for 15 days. Outcomes were assessed at baseline, immediately after the program and at three months follow-up.

Results: Significant post-intervention improvement was seen on all primary and secondary outcome measures; personal goals (GAS score; COPM performance and COPM satisfaction), daily activities (*ACTIVLIM*), hand function (ABILHAND-Kids), mobility (ABILOCO-Kids; GMFM-66-IS score). There was no loss to follow up during the program and after three months. At follow-up, improvements were retained except for ABILOCO and GMFM-66-IS.

Conclusions: Functional intensive therapy appears feasible and seems to be effective in improving treatment goals focused on mobility and self-care, even in older and more severely affected children and adolescents with CP. After three months, these possible effects were still present.

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KEYWORDS
Functional intensive therapy; mobility and self-care; gross motor function; cerebral palsy; adolescents; ICF-CY

➤ IMPLICATIONS FOR REHABILITATION

- Short intensive functional training is feasible and showing no loss to follow up in the older and more severely affected children and adolescents with cerebral palsy (CP).
- Short intensive functional training appears effective in improving individual goals in children and adolescents with CP and improvements endorse three months.
- Short intensive functional training seems to be effective on both mobility and self-care domains of the ICF-CY.

Introduction

Cerebral palsy (CP) is a major cause of disability in children during development, as it affects around two out of every 1000 children [1,2]. Gross motor function is affected in children with CP. This impairment, a result of brain lesions in the developing brain, causes problems to manage and perform daily activities efficiently and independently [3,4]. The limited ability to perform activities of daily living (ADL) restricts the participation of these children at school, during leisure time and sports. Limitations in capacity and performance and the limited ability to adapt to the environment are underlying this poor performance in ADL [3,4].

Many interventions have been developed to improve this poor performance in ADL in children with CP [5–7]. Interventions consisting of functional and intensive components have proven to be most effective in improving motor performance in these children [7–12]. According to the Dutch guidelines, a therapeutic intervention is classified as functional when the following criteria are met: (I) goal oriented; (II) focused on activity/participation; (III) task-specific; (IV) active role for both the child and the parent/caregiver in learning/discovering/finding solutions for problems; (V) aimed at functionality instead of normality; (VI) context-specific [13]. The classification of interventions as intensive or non-intensive depends on frequency and duration of both the separate therapy sessions and the intervention in general. Therapy is intensive when applied over three times per week, with a longer duration compared to normal therapy sessions [7,14,15].

Often, functional and intensive interventions are focused on either lower- or upper extremities, but interventions focusing on activities combining upper and lower extremities, a prerequisite to perform ADL independent and efficient, remain scarce

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[6,12,15]. The few studies that did focus on the combination of upper and lower extremities revealed to be efficacious in improving gross motor function and functional activities, resulting in improvement in self-care and participation [7,16,17]. Bleyenheuft et al. developed the Hand and Arm Bimanual Intensive Therapy Including Lower Extremity (HABIT-ILE) intervention and found significant improvements in functioning of both extremities following HABIT-ILE in children with unilateral CP, aged 6–13 years and GMFCS level I and II [18]. Due to restrictions in age groups and distribution of CP classifications in previous studies, results of this type of intervention cannot yet be generalised to other (older) age-groups and more severely affected (i.e., GMFCS III and IV) children and adolescents with CP. To our knowledge, only one study focused on the relationship of motor impairments to motor function and self-care, mobility and participation in children with CP [19]. This study was aimed at young children aged 1–4 years.

Aim of the present study is to assess the effectiveness of a 15-days functional, intensive, goal-oriented therapy program, called FitCare4U, focused on improving individual goals in the domain of mobility and self-care in children and adolescents with CP, GMFCS classification I–IV, aged between 11 and 20 years old.

Material and methods

Population

A convenience sample of children and adolescents diagnosed with CP, who participated in the FitCare4U therapy programs between 2014 and 2018 was used. The following inclusion criteria were used: (I) GMFCS classification I–IV (able to stand/transfer independently); (II) between 11 and 20 years old; (III) unilateral or bilateral CP (spastic/dyskinetic/ataxic); (IV) have clear treatment goals in the domains of mobility and self-care. Exclusion criteria were: (I) unable to sleep over and be away from home for the duration of 15 days and (II) severe cognitive impairments that hindered active participation in the program. Participation in FitCare4U was based on recommendation of the treating rehabilitation physician and his or her team. Informed consent from parents and children was obtained.

Intervention

FitCare4U [11,20,21] is a 15-day functional intensive therapy program developed by researchers and clinical staff of Adelante Paediatric Rehabilitation Centre in Houthem, The Netherlands. Before the start of the program every participant formulated their own personal treatment goals and needs, focused on domains of mobility and self-care. Together with the therapist and parents, these goals were ranked into a top three. Performance of these three goals was assessed, and after a task analysis, they were translated into individualised goal-directed therapy sessions. All training was performed on site.

During the 15-day intervention period, participants received a daily total of 6–7 h of intensive therapy, amounting in total to 80–90 h for the entire program. To guarantee this intensity, time on task of each participant was monitored by a personal buddy, who was also coach. These buddies, mostly students of physiotherapy, movement science or sports training, were supervised by professionals of Adelante. The students participated in exchange for education credits or as part of their graduation internships. In terms of manpower, one healthcare professional managed three children with CP.

A weekday consisted of a normal school program in the morning, followed by a therapy block of 90–120 min in which the specific personal treatment goals were trained. The rest of the daily program consisted of 5–6 h of functional, intensive group activities (e.g., climbing, walking, swimming, self-defence sports, etc.), again in therapy blocks of 90–120 min. During the group activities, personal goals on mobility were incorporated as much as possible. For example, the participant's seating could be adapted to make a task more challenging, e.g., a ball instead of a chair. In addition, buddies continuously stimulated their participants to walk and sit independently, tried to limit the use of aids, and encouraged an active posture during all activities.

A weekend day consisted of therapy sessions directly from the moment of waking up. First, self-care activities were practised. Second, breakfast had to be prepared by themselves. Third, they had to train personal goals together with family members to improve retention of the trained skills in the home environment after the end of the therapy program. Fourth, in order to increase retention of learned skills even further a focus was laid on experiencing family focused activities. As the chance that the learned skills will continue to be applied is higher this way. For instance, doing a steep forest walking trail in teams of children and their parents

Primary outcome measures

Goal Attainment Scaling (GAS) is an evaluative tool to assess personal treatment and/or intervention goals on a six-point scale, ranging from −3 to +2. The participant's performance was scored −2 at baseline and improvements in the performance of the goal were scored ranging from −1 to +2, where −3 reflects deterioration and 0 corresponds to the expected outcome [22]. Psychometric properties of the GAS in children with CP have been evaluated and proven good content validity and responsiveness. GAS showed excellent intra-rater and inter-rater reliability, with ICCs of 0.96 [23]. Changes of two points or more are defined as a clinical relevant difference [24].

For each participant, the most important rehabilitation goal, was translated into a GAS by the professionals of Adelante. They defined predetermined criteria for the progress towards that specific rehabilitation goal. The individual's performance of this primary goal was filmed at baseline, after the end of the program and at follow-up. These video recordings were randomly scored by several testers. These testers were aware of the fact that the child participated in an intensive therapy programme, however, were blinded for measurement time and exact therapy content.

Canadian Occupational Performance Measure (COPM) is a semi-structured interview, in which participants identify and rank their perceived problems in activities of mobility and self-care. The approach of this measure corresponds to the goal-oriented approach of the therapy program. The primary problem corresponds to the most important rehabilitation goal. The perceived performance and satisfaction of the top three goals was scored on a scale of 1–10, resulting in an averaged total performance and satisfaction score. The COPM has good construct-, content-, and criterion validity. Test–retest reliability is high (0.76–0.89), other ICC values of reliability remain to be tested in this population [25]. COPM performance and satisfaction was scored by the parents. Changes of two points or more were classified as clinical relevant differences [26].

Secondary outcome measures

The secondary outcome measures consisted of four questionnaires. All questionnaires were scored by the parents, as they

proved to give a more accurate assessment of their child's abilities and limitations.

Daily activities were measured using the ACTIVLIM [27]. ACTIVLIM is a 22-item questionnaire measuring perceived limitations in daily activities for children with neuromuscular disorders due to impaired function of upper- and/or lower-extremities [28]. ACTIVLIM items are scored on a three-point ordinal scale: 0 (impossible), 1 (difficult), or 2 (easy). With a reliability ICC of 0.96 and reproducibility ICC of 0.93 it is a valid instrument [27].

Hand function was assessed using the ABILHAND-Kids [29]. ABILHAND-Kids is a 21-item questionnaire measuring perceived bimanual ability in children with CP. The ABILHAND-Kids is scored on a three-point scale, analogue to the ACTIVLIM [30]. With a reliability ICC of 0.94 and a reproducibility ICC of 0.91, the ABILHAND-Kids is a valid measurement to report (changes in) perceived manual function in children with CP [29].

Mobility was measured using the ABILOCO-Kids and GMFM-66-IS. *ABILOCO-Kids* is a 10-item questionnaire measuring perceived ability of locomotion focusing on impairments in the lower extremities [31]. The items are again scored on a three-point ordinal scale: 0 (impossible), 1 (difficult), or 2 (easy). The reliability and reproducibility (ICC) of this test are 0.97 and 0.96, respectively [32].

Gross Motor Function Measure 66 Item Set (GMFM-66-IS) is a shorter version of the GMFM-66. The latter is an updated version of the GMFM-88 [33,34]. Items are divided into five main categories: (I) lying and rolling; (II) sitting; (III) crawling and kneeling; (IV) standing; and (V) walking, running, and jumping and scored on a four-point Likert scale [33]. The GMFM-66-IS shows excellent agreement with the GMFM-66 (ICC = 0.994) and sensitivity to no change, small or large differences in motor function [34]. Test–retest reliability of the Dutch version (used in this study) lies between 0.96 and 0.99 [35]. GMFM-66-IS tests were performed with participants wearing shoes and orthosis, since this resembles everyday situations.

Data analysis

Data were collected prospectively at three different time points. Baseline measurements were collected 14 days before the initial start of the therapy program (PRE). Immediately post-intervention measurements were taken within 10 days after the end of the intervention (POST). Follow-up measurements were taken at three months follow-up (FOLLOW-UP). In the case of the follow-up measurements, these could be recorded up to 4 months after the end of the therapy program due to the intervening summer holidays. Parametric statistics was used, based on the Central Limit Theorem [36]. One-way ANOVA repeated measures and post hoc analyses were performed to assess the effect of time on outcome measures. To test the assumption of sphericity, Mauchly's test of sphericity was used. Significance levels were corrected for multiple comparisons using Bonferroni's test. Results of the ABILOCO-Kids, ACTIVLIM, and ABILHAND-Kids were transferred to logit scores using the Rasch analysis. Children and youth classified as GMFCS IV, act from a seated position (usually supported) as their self-mobility is limited. They are more likely to be transported in a manual wheelchair or use powered mobility. For this reason, these children ($n = 9$) were excluded from data analysis of the ABILOCO-Kids. Furthermore, intention-to-treat analysis was used. Data were analysed using IBM SPSS Statistics version 25 ((IBM SPSS Statistics, IBM Inc., Armonk, NY). Statistical significance was set at $p < 0.05$. Changes per identified goal are described and classified in differences below or above the minimum clinically important difference (MCID).

Results

Participants

Thirty-five children, 16 boys (45.7%) and 19 girls (54.3%), were analysed. Mean age at the beginning of the intervention was 14.5 (±2.2) years, ranging from 11 to 19 years. Patient characteristics of the study sample are presented in Table 1. There was no drop-out of participants during the program and at three months follow-up.

Primary outcome measures

GAS

Immediately after the intervention, 33 out of the 35 participants had reached, or exceeded their personal treatment goals (GAS $\geq$0). Eleven children showed an improvement of four points, 13 children improved three points, and nine children two points on the GAS. These were all clinical relevant differences (GAS $\geq$2). One child showed one point improvement from baseline and one child revealed no improvement. At three months follow-up, all participants had reached or exceeded their personal goals. At this point, 21 children showed an improvement of four points, seven children showed an improvement of three points and seven children improved two points on the GAS. In other words, the improvement in all children at follow-up exceeded the MCID of two points. A visual presentation of GAS improvements is shown in Figure 1. This improvement was statistically significant. The GAS scores of the primary treatment goal showed a positive effect over time ($F(1.67, 354.48) = 142.08$, $p < 0.001$). Post hoc pairwise

Table 1. Descriptive data of participants ($N = 35$).

Gender, male/female	16/19
Distribution of CP, unilateral/bilateral	8/27
GMFCS I	5
GMFCS II	11
GMFCS III	10
GMFCS IV	9
MACS I	11
MACS II	12
MACS III	11
MACS IV	1

GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System; *N*: number.

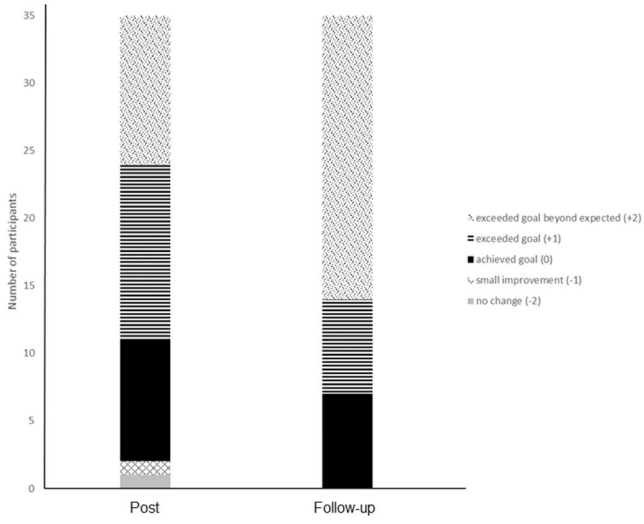

Figure 1. GAS improvements post-intervention (POST) and at 3 months follow-up (FOLLOW-UP).

comparisons revealed a significant improvement between pre- and post-scores and between pre- and follow-up scores ($p < 0.001$). The improvement between post-test and follow-up-scores (0.49 ± 0.11) was also significant ($p < 0.001$).

COPM

In total, 104 rehabilitation goals were formulated using the COPM. Three goals were prioritised per person with the exception of one child. This child identified only two treatment goals. The goals were all classified according to the activity and participation domains of the ICF-CY: mobility (d4) and selfcare (d5). An overview of the domains per participant and their corresponding COPM performance and satisfaction scores is given in Table 2. Seventy-three treatment goals focused on the mobility domain, 29 goals on the selfcare domain. Two goals were found to fall in the Domestic life domain (d6).

The distribution of the goals as a primary, secondary, or third treatment goal is depicted in Figure 2.

A closer look at the individual COPM performance scores reveals that 32 out of 35 children improve on their primary goal. One child's performance is scored worse after the therapy program and in two children the performance is rated unchanged. These results are retained in 31 children at three months follow-up. As to the secondary goal, 34 children showed an improvement in COPM performance score and one child did show an unchanged score. These results were retained at three months follow-up. The COPM performance score for the third goal improved in 31 out of 34 children (as one child did not have a third goal). Two children scored unchanged and one child deteriorated. At three months follow-up, 30/34 children maintained their improved COPM performance scores. COPM satisfaction scores reveal a similar improvement. In addition, the majority of the children showed an improved COPM score exceeding the MCID of two points. Figure 3 depicts a complete overview. One-way ANOVA repeated measures resulted in a statistically significant positive effect over time on outcomes for COPM-performance and COPM-satisfaction ($F(1.459, 52.409) = 157.610$, $p < 0.000$) and ($F(1.463, 52.685) = 134.924$, $p < 0.000$), respectively. COPM-performance and COPM-satisfaction, both post- and follow-up test scores revealed to be statistically significantly higher compared to pre-test scores ($p < 0.001$).

Secondary outcome measures

ACTIVLIM and ABILHAND-Kids revealed statistically significant p values for Mauchly's test ($\chi^2(2) = 10.54$, $p < 0.05$) and ($\chi^2(2) = 10.31$, $p < 0.05$), respectively, violating the assumption of sphericity. ACTIVLIM and ABILHAND-Kids reported ($F(1.533, 45.987) = 14.451$, $p < 0.001$) and ($F(1.529, 44.343) = 8.594$, $p < 0.05$), respectively, indicating a statistically significant positive effect over time on outcomes. For ABILOCO-Kids, sphericity was assumed ($\chi^2(2) = 0.57$, $p = 0.75$). One-way ANOVA repeated measures revealed a statistically significant positive effect over time on ABILOCO-Kids scores ($F(2, 50) = 6.915$, $p < 0.05$). The immediate post-intervention scores of ACTIVLIM, ABILHAND-Kids, and ABILOCO-Kids were all statistically significantly higher compared to pre-test scores. Comparing pre-test scores to follow-up test scores resulted in statistically significant positive differences for ACTIVLIM and ABILHAND-Kids.

Regarding GMFM-66-IS scores, Mauchly's test revealed that the assumption of sphericity was violated ($\chi^2(2) = 12.29$, $p < 0.05$). Results of the one-way ANOVA repeated measures showed a significant positive effect over time on GMFM-66-IS outcomes ($F(1.465, 10.065) = 5.496$, $p < 0.05$). A graphic representation of the change over time for these outcome measures is presented in Figure 4.

Discussion

The aim of this study was to assess the effectiveness of a 15-days clinical therapy program (FitCare4U), focused on improving individual goals in the domain of mobility and self-care in children and adolescents with CP, GMFCS classification I–IV, aged between 11 and 20 years old. It was shown that even in this older age group and more severely affected children intensive, functional, goal-oriented therapy involving both the lower and upper extremities may be used to improve personal goals within the ICF mobility and self-care domains. Improvements were retained at three months follow-up, whereas GAS even further improved, stressing the importance of functional, goal-oriented therapy. Additionally, it can be concluded that this form of intensive therapy is feasible for this patient group as there were no drop-outs during the program or at follow-up.

Improvements in primary outcome measures

Improvements in personal goals, reflected by a higher GAS score, means a better execution of these activities in daily life. Post-intervention, the average score was 0.91, meaning that participants reached, and even exceeded their initial performance. Follow-up scores even show greater improvement compared to immediately after intervention scores (1.40), indicating that participants tend to reach the maximum score on the GAS over time. This is a promising finding, since improvement in execution of activities in daily life setting (participation) results in an increase in independence and, consequently, quality of life. The results suggest that direct training of functional goals that are important to the child, may elevate the likelihood of transfer and generalisation to daily life.

Parents were also very satisfied with the effects of the program as they rated the performance and satisfaction of the personal goals by their child higher immediately post-intervention and at three months follow-up. These improvements constitute clinically meaningful change, since the majority of the COPM scores surpassed the MCID of two points, both immediately post-intervention and again at three months follow-up timepoint [37]. These changes are in line with a study of Bleyenheuft et al., reporting on intensive intervention effects in substantially younger and less severe affected populations [8]. Importantly, we were able to show these results may be generalised to children and adolescents with CP with a broad age range and broad GMFCS range.

Improvements in secondary outcome measures

In addition to the primary outcome measures, the children also showed improvement on all secondary outcome measures after intervention. Improvements were retained at three months follow-up, except for ABILOCO-Kids and GMFM-66-IS. The scores on these outcome measures showed a deterioration at follow-up. Results are in line with other literature reporting improvements as a result of comparable interventions, showing improved functioning of upper- and lower extremities in younger and less affected populations [8,38–41]. The relapse at follow-up might be explained by the fact that during the intervention, in addition to training for the personal treatment objectives, there was also continuous attention for gross motor skills. This was perhaps less the case after the programme had ended. The Rahlin study may shed

Table 2. Individual goals according the ICF-CY classification ($n = 104$) and their COPM performance and satisfaction score.

Child	Age	GMFCS	MACS	Primary goal	P-pre	P-post	P-follow-up	S-pre	S-post	S-follow-up	Secondary goal	P-pre	P-post	P-follow-up	S-pre	S-post	S-follow-up	Third goal	P-pre	P-post	P-follow-up	S-T0	S-T1	S-T2
1	14	4	1	d450	6	4	999	3	6	999	d420	1	8	8	1	8	8	d450	5	8	7	4	9	7
2	11	4	3	d465	5	5	5	4	4	4	d420	1	7	4	1	7	4	d520	4	6	4	2	6	4
3	15	3	1	d420	7	7	7	8	7	7	d450	5	6	6	4	5	5	d510	7	6	6	7	6	6
4	18	4	1	d540	4	7	8	3	7	7	d465	3	7	7	3	8	8	d420	3	8	8	4	7	8
5	15	2	2	d450	3	6	6	3	6	5	d520	4	7	7	4	7	7	d540	2	10	8	5	10	8
6	14	3	2	d540	1	6	7	1	6	7	d540	5	6	6	4	6	7	d540	5	6	7	5	6	7
7	16	4	1	d420	6	8	7	5	9	8	d469	4	7	7	5	7	8	d415	1	8	6	1	7	6
8	14	3	2	d450	6	8	7	6	8	8	d430	4	5	8	4	7	8	d415	6	6	7	6	6	8
9	15	2	3	d430	3	5	6	3	6	6	d420	3	6	7	4	7	6	d450	0	7	5	0	6	5
10	16	4	3	d450	3	5	6	3	5	5	d420	2	7	7	3	7	7	d510	4	6	5	5	6	4
11	14	4	3	d540	5	7	6	3	5	5	d450	6	7	7	2	5	6	d520	0	7	6	0	7	7
12	15	3	3	d410	5	7	7	5	6	6	d410	6	8	7	6	8	6	d415	6	7	6	6	7	7
13	15	3	2	d510	5	8	8	5	9	8	d520	6	8	8	6	9	9	d430	0	8	8	0	8	7
14	13	4	2	d450	5	8	8	5	9	7	d510	0	8	8	0	7	8	d510	5	8	8	5	8	7
15	17	2	2	d450	5	8	7	5	8	8	d451	5	8	8	4	8	8	d540	5	8	7	3	8	7
16	18	2	2	d460	5	7	6	6	7	6	d540	1	1	1	1	1	5							
17	12	2	1	d460	3	6	3	3	6	3	d540	3	6	5	3	6	5	d630	3	5	5	3	5	5
18	11	1	1	d460	2	5	7	2	6	8	d450	2	5	7	2	6	8	d450	5	6	8	1	7	8
19	18	2	2	d469	2	7	7	2	7	7	d510	2	7	6	4	7	6	d540	1	7	7	1	7	7
20	15	1	1	d469	5	7	7	5	7	7	d450	5	7	7	5	7	7	d410	4	5	7	4	5	7
21	19	3	1	d429	5	8	8	5	9	7	d451	1	6	8	1	6	6	d430	5	8	8	5	9	9
22	12	2	1	d450	4	8	8	1	8	8	d540	4	8	8	5	8	8	d430	6	8	8	6	8	7
23	12	2	1	d450	4	7	8	4	8	7	d430	2	7	8	2	8	7	d430	5	9	8	5	8	9
24	13	3	2	d450	2	6	6	6	7	7	d430	1	7	8	1	7	8	d415	2	6	6	2	5	5
25	12	4	2	d465	5	7	6	6	6	7	d420	5	8	7	6	7	7	d445	6	8	6	7	7	5
26	15	2	3	d540	1	6	8	1	7	9	d550	1	6	8	1	7	8	d640	5	6	7	6	6	7
27	13	3	2	d465	4	6	5	3	6	5	d465	2	6	6	2	6	6	d450	1	1	1	2	2	1
28	15	4	3	d420	3	8	7	3	8	7	d420	3	4	5	3	4	3	d420	3	8	8	3	8	8
29	14	1	3	d440	1	6	7	1	7	6	d510	5	9	10	5	9	10	d540	1	6	3	1	6	5
30	13	3	2	d465	6	8	7	4	8	9	d449	1	8	9	4	8	9	d450	5	8	7	5	8	8
31	16	2	1	d469	5	6	7	3	7	8	d430	3	7	7	4	7	8	d420	1	8	7	4	8	8
32	15	1	3	d450	6	10	9	4	10	9	d540	1	10	9	1	10	9	d540	1	8	8	1	8	8
33	12	1	3	d540	1	4	6	2	5	7	d410	3	7	8	1	8	9	d520	2	6	6	1	7	7
34	19	4	3	d450	4	8	5	4	8	4	d450	4	8	7	5	8	6	d415	3	8	8	3	8	6
35	11	2	1	d450	1	8	6	2	9	6	d450	3	7	6	4	7	6	d430	1	6	6	2	6	6

GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System; *N*: number; P: COPM performance score; S: COPM satisfaction score; pre: pre intervention; post: post intervention; follow-up: three months follow-up; 999: missing value; child #16 had only two goals; d4 MOBILITY; d410–d429 Changing and maintaining body position; d430–d449 Carrying, moving, and handling objects; d450–d469 Walking and moving; d470–d489 Moving around using transportation; d498 Mobility, other specified; d499 Mobility, unspecified; d5 SELF-CARE; d510 Washing oneself; d520 Caring for body parts; d530; d540 Dressing; d550 Eating; d560 Drinking; d570 Looking after one's health; d598 Self-care, other specified; d599 Self-care, unspecified; d6 DOMESTIC LIFE; d610–d629 Acquisition of; d630–d649 Household tasks; d650–d669 Caring for household objects and assisting; d698 Domestic life, other specified; d699 Domestic life, unspecified.

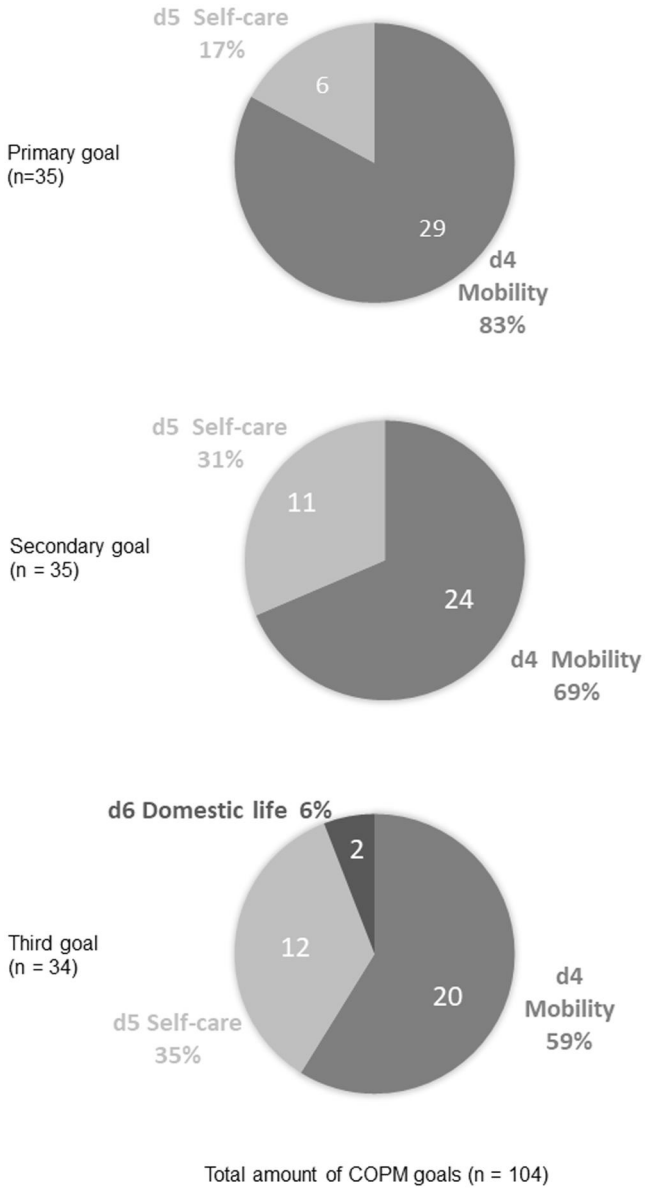

Figure 2. Distribution of personal treatment goals according to the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY).

more light on the matter. Rahlin et al. are performing a systematic review on how intensity of physical therapy affects the Gross Motor Function Measure (GMFM-66) total score in children with CP [42]. The ABILOCO is known to correlate to the GMFM [43].

The overall MCID for the GMFM-66 was found to be 1.3 with a large effect size (0.8), and 0.8 with a moderate effect size (0.5) [44]. The difference between pre- and post-test scores shows an improvement that is well above the MCID of 1.3. The difference between pre- and follow-up scores is still above the moderate effect size MCID. No other study using functional intensive therapy has been performed in this older age and more affected group. In comparable studies, the ages ranged from very young, 28 months [39], 3–4 years [40], and 8–11 years [8,18,38,41].

Therefore, results of this study substantially extent the knowledge about effective rehabilitation interventions for older children and adolescents with CP, including all levels of GMFCS classification.

Age related motor function improvements in children and adolescents

The large improvements in gross motor function are somewhat surprising since participants in this age group are normally not expected to show results of this magnitude. Children with CP tend to reach 90% of their motor development potential at younger ages than typically developing children [45,46]. Children with GMFCS level I are thought to reach this potential for 90% at 4.8 years old, levels II–V respectively 4.4, 3.7, 3.5, and 2.7 years old [46], but not at ages ranging from 11 to 19 years. It is expected that changes in learned (motor) behaviour are more difficult to achieve in adolescents compared to young children [45].

Therefore, increases in performance as a result of this intervention are more likely to be a result of motor learning, improved strength and familiarity with activities and seem relatively independent of age. This demonstrates the efficacy of functional intensive therapy programmes in children and adolescents with CP [39,40,45] and is very promising for future implementation of intervention programmes in older age groups.

Intervention characteristics underlying changes

The group training and the social aspect of the intervention, as well as the involvement of the parents in the weekend activities, are said to have a positive influence on the performance of activities in daily life after the intervention. Follow-up measures showed that improvements as a result of the intervention were sustained to a certain level, and GAS scores even improved at follow-up. This may be ascribed to the fact that participants were motivated to continue several aspects of the intervention at home or in their standard physical therapy sessions, as observed in comparable interventions [47–49]. The involvement of the parents in the program (during the weekend program) may have contributed to this positive development. This was what parents indicated during the evaluation sessions [20].

The intensity and high dose of therapy sessions may also have contributed to the improvements in motor function and performance of ADL. Interventions of comparable intensity all reported similar statistically and clinically significant results, both in post- and follow-up measurements [7,9,10,50], indicating that this type of intervention may also be beneficial for older children and adolescents.

Another important characteristic is the goal-directed approach. Therapy being "goal directed" is considered a very important component of therapy [51]. Personal therapy goals were based on limitations in ADL (e.g., walking without assistance, dressing, and eating/cutting food), related to mobility and self-care through the domains of activity and participation of the International Classification of Functioning Disability and Health for Children and Youth (ICF-CY) model. Studies have found that goal performance increased superior to other outcome measures when goals were practiced during the intervention [9,47], which occurs in very high doses during FitCare4U.

Limitations

This is a prospective clinical study, lacking a formal control group. Each participant served as his own control. Therefore, the level of evidence of the efficacy of our program is limited (3 on the Oxford 2011 Levels of Evidence [52]). However, to date, no other study reports on the efficacy of a clinical rehabilitation interventions like FitCare4U in children and adolescents, GMFCS level I–IV, and aged between 11 and 20 years old. Therefore, this study

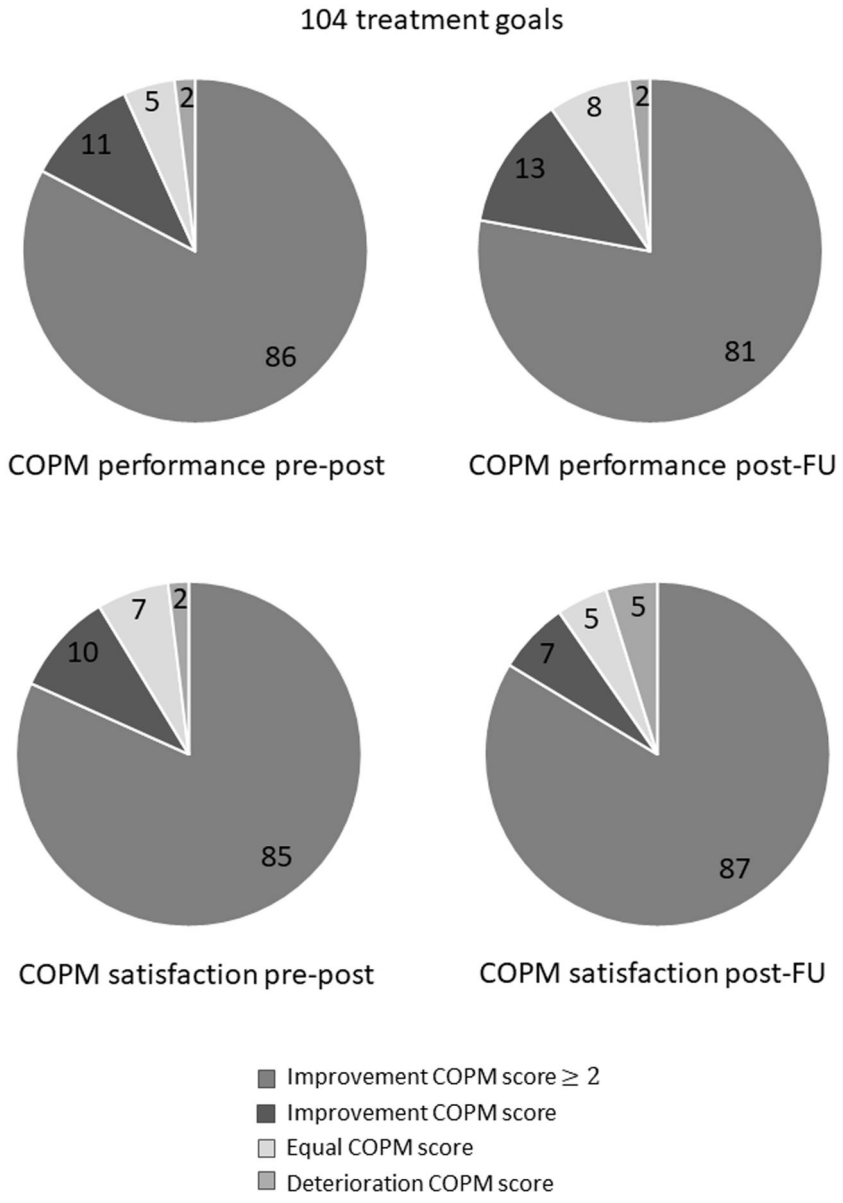

Figure 3. Changes in COPM performance and satisfaction scores between start and end of the intervention (PRE-POST) and between the end of the intervention and follow-up (POST-FU).

adds to evidence of the effectiveness of clinically applicable functional, intensive, goal directed therapy.

To improve the quality of the evidence, future studies should have a larger sample size and a control condition (e.g., waiting list control group), even though participant masking is not possible. The ABILOCO-Kids questionnaire is a valid and reliable tool to assess perceived difficulty with locomotion and has been calibrated in children with CP [32]. Though use of the adult version of ABILOCO could have been considered for the older participants, since the kids-version was calibrated in a group with mean age of 10 years old. The same applies to the ABILHAND-Kids and the adults version of the ABILHAND [53]. However, for practical reasons and for the fact that all participants were older than 10 years we decided to use the "kids" version of both scales. Recently, a specific version of ACTIVLIM, aimed at the CP population, was published, ACTIVLIM-CP [54]. However, when we designed the clinical program this instrument was not yet available.

GMFM-66-IS tests were performed with participants wearing shoes and orthosis, which is not according to guidelines. However, we decided for this practice to fit the measurements in a clinical training program and not to lose too much time. As the GMFM-66-IS was assessed this way during all three measurement sessions, we considered the within-subject comparison valid and reliable.

Conclusions

FitCare4U seems to be effective in increasing the level of mobility and self-care in children and adolescents with CP, regardless of GMFCS level or age. The short duration of the program, combined with the high amount of daily therapy hours, aimed at functional and goal-oriented therapy, in a social and fun context, involving parents certainly contributed to the success [10,49,55]. This also contributed to the fact that the programme was easy to maintain for the participants despite the intensity of training. Confirmation

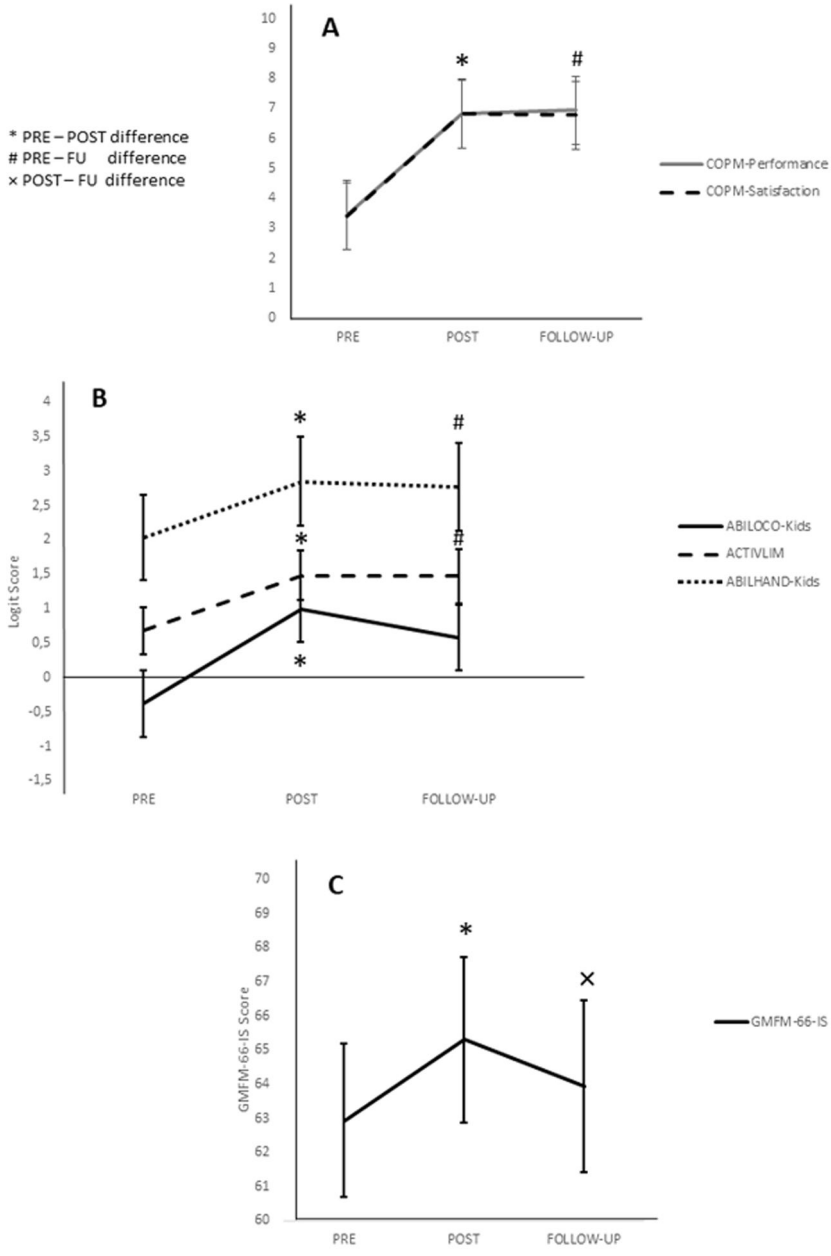

Figure 4. (A) COPM performance and satisfaction scores over time. (B) ACTIVLIM, ABILOCO, and ABILHAND-Kids scores over time. (C) GMFM-66-IS scores over time.

in a larger population with ideally a control condition is needed to confirm these results at a higher level of evidence.

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Appendix 1

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