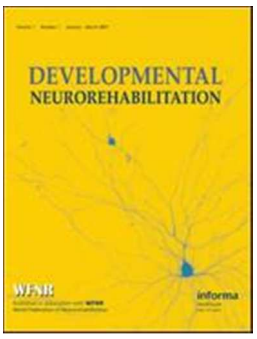

The effects of a Conductive Education course in young children with cerebral palsy: a randomised controlled trial

Journal:	*Developmental Neurorehabilitation*
Manuscript ID	TPDR-2017-0002.R1
Manuscript Type:	Original Research
Keywords:	Conductive Education, Children, Cerebral palsy, Conventional practice, Randomised controlled trial

Title: ~~No added~~ ~~The~~ ~~short term e~~Effects of a Conductive Education course in young children with cerebral palsy: a randomised controlled trial

Abstract

Aim: To evaluate the effects of a conductive education (CE) course followed by conventional practice, on gross motor function, other functional skills, quality of life and parents' experiences of family-centred services in young children with cerebral palsy (CP).

Methods: Twenty-one children with CP, 3-6 years old, were randomised to one three-week CE course followed by conventional practice or conventional practice on a waiting list. Outcomes were measured four months after baseline. A web-based log collected data on the conventional practice.

*Results: N*o additional improvements in the children's outcome were found. However, parents in the CE group reported that they received more information than parents in the waiting list group (p=0.01). Children in both groups performed high amount of conventional practice at home.

Conclusions: A three-week CE course did not add any improvements in the children's functioning, possibly explained by the large amount of conventional practice reported of both groups.

Introduction

Conductive Education (CE) is one of many interventions that are offered to young children with cerebral palsy (CP) [1, 2]. CP is defined as a complex condition that involves motor impairments, activity limitations, and participation restrictions that are caused by a lesion in the immature brain [3]. According to the philosophy of CE, the consequences of CP are considered a learning problem and, accordingly, must be met with educational principles [4]. The aim of CE is to assist children with motor dysfunction to attain independence in daily activities according to their functional level [5]. CE is characterised by the use of CE-equipment (e.g., slatted wooden tables and ladder back chairs), structured training programs in groups, facilitation by a CE conductor (specially trained CE teachers of college level training), rhythmical intention performed as rhythmical speech, counting or singing to reinforce movement and task series to gain control and to learn new movements [6].

The spread of CE from Hungary to many countries has contributed to a variety of CE training models [4]. Thus, it is difficult to summarise studies and generalise the results. When summarising the effects of CE, reviews have shown inconclusive and contradictory effects [1, 2]. The evidence base of CE is typically characterised by non-randomised controlled trials with low methodological quality [2, 7] and outcome measures with unknown psychometric properties [2].

In Norway, CE training is offered at specific PTØ-centres, typically as three week courses every four month and performed adjacent to conventional practice. Recent Norwegian surveys indicate that conventional practice is most commonly performed as functional training (e.g., targeting walking, eating and playing) integrated in daily activities at home and in kindergarten led by physiotherapists, parents or other caregivers of the child [8, 9]. As far as

we know, only two~~one~~ studies [10, 11] haves investigated the effects of a CE course followed by conventional practice. However, the most current ~~is~~ study [10] did primarily included school-aged children and did not describe the content of conventional practice, whereas the older [11] did.~~, and compared the effects of a four-week modified CE course to another intensive training program after one year.~~ Therefore, randomised controlled trials that describe the essential components of CE and additional conventional practice and assess both the benefits and harms of CE using validated outcome measures are needed.

The primary aim of the current study was to evaluate the effects of a three-week CE course followed by conventional training compared to conventional training on a four-month waiting list on the gross motor function of young children with CP. The secondary aim was to compare the effects on the child's functional skills and quality of life, parents' quality of life, and their experiences of family-centred services.

Method

Design

This study was conducted as a randomised controlled trial and completed in accordance with the CONSORT statement [12~~1~~]. A protocol was registered at www.controlled-trials.com with registration number [redacted]. The Regional Committee for Research Ethics in Norway approved the study protocol (approval number [redacted]). All participants gave written informed consent before data collection began. The children were randomised to participation in the first available CE course or to the waiting list for 4 months, in the order in which they were included into the trial. A fixed block randomisation list was made using the software randomisation.com. The block size was four, and for every fourth child included,

two were immediately assigned to the CE course and two were assigned to the waiting list. A statistician who was not associated with the trial performed the randomisation and kept the randomisation list concealed from the researchers and assessors. When informed consent was received, the study-coordinator at the PTØ-centre called the statistician, informed the statistician of the new inclusion, and asked for the random allocation status of the newly included child. Only the three physiotherapist assessors were blinded to the group assignment at baseline and the follow-up assessments. The parents were also reminded to conceal the group assignment from the ~~three~~ assessors.

In the current paper ~~the short-term~~ effects of one CE course was compared to conventional practice on a waiting list to secure an appropriate and optimal reporting of the short-term effects. A twelve months follow up of the CE courses will be presented in another paper, as the analysis of long-term effects and trends over time requires advanced statistical methods based on repeated measures, in which short-term effects might be diluted because of the possibly limited sample size. The CE group continued the conventional practice after the CE course and the waiting list group only performed conventional practice. Parents reported the conventional practice in a web-based log once per month (appendix).

Participants and selection criteria

The inclusion criteria were: children aged 3-6 years old with all types and functional levels of CP according to the Gross Motor Function Classification System E&R (GMFCS) [3] and who were eligible for CE courses after assessment by the CE-conductors at two PTØ-centres. The parents of the eligible children had to write and read Norwegian fluently. The exclusion criteria were: Children with prior experiences with CE courses and who were not suitable for group training. The inclusion of participants started in October 2010 and ended in September 2014.

All eligible children participated. Once the child was evaluated as eligible for CE courses, a CE-conductor informed the parents of the current study. Then, the first author sent additional information, and written informed consent was obtained from the parents who accepted to participate with their child.

Intervention

The children were randomised to the first available CE course (CE group) or to four months on a waiting list (waiting list group) before enrolment in their first CE course at one of the PTØ-centres. The CE course was provided in groups of four to six children and split into walkers or non-walkers. An experienced Hungarian conductor who spoke Norwegian ran the training together with a Norwegian conductor, and one to three additional assistants depending on the need. The training was run four hours per day, five days per week for three weeks, as typically done at the PTØ-centres in Norway for this age group. The CE course contained structured training programs that targeted standing, sitting, walking, lying, arts and crafts, and specific child-parent-conductor set goals. The children also performed daily training that targeted eating and drinking, getting dressed, and toileting. Use of CE-equipment and rhythmical intentions were included in the training. Each course had an underlying topic (such as "driving school" with Postman Pat) that was incorporated into the daily training program. The children were encouraged to select the topic of the course and the different activities. The parents were not trained to carry on with the CE training at home at the first course.

Outcome measures

The primary outcome measure was the Gross Motor Function Measure 66 (GMFM-66) [132]. The GMFM-66 is a criterion-referenced observational tool that captures the child's gross

motor capacity in a standardised environment. The items are scored on four-point ordinal scales (0=cannot initiate; 1=initiates; 2=partially completes item; and 3=completes item independently) [13]. If the child omits an item or is unable, or unwilling to attempt, the item is scored as 0. The interval scores range from 0 (lowest motor function) to 100 (highest motor function). The GMFM-66 has shown to be reliable (ICC 0.99), valid and sensitive to change [132], also in a Norwegian population [143]. The GMFM-66 total score was calculated using Gross Motor Ability Estimator (GMAE) software which transfers the raw scores into an interval scale as a result of Rasch analysis.

Secondary outcome measures for children and parents

The Paediatric Evaluation of Disability Inventory (PEDI) [154] was used to capture the children's capability to perform functional skills in their natural environment in daily life. The PEDI was administered as a structured interview with the participating children's parents. The current study used the functional skills scales, which include 73 self-care items, 59 mobility items and 65 social functioning items, each scored as "unable" (0) or "able" (1) by the interviewer. The raw aggregated scores are transformed into scaled scores (0-100), indicating increasing levels of functioning, that are used to identify change in performance [154]. The PEDI has been tested for reliability (ICC 0.64-0.74) and validity in a Norwegian population [165, 176].

The child's health-related quality of life was assessed using the Paediatric Quality of Life Inventory (PedsQL) [187], parent-proxy report for children aged 0-4 years. The PedsQL contains four scales: physical (8 items), emotional (5 items) and social functioning (5 items) and functioning in kindergarten (3 items). The respondents report the degree to which these

items are a problem on a 5-point scale (0=never, 5=almost always). Higher scores indicate increased problems. This questionnaire has been found to be reliable (Cronbach's alpha 0.77-0.88) and valid in a Norwegian context [198].

The parents' global quality of life was measured using the Norwegian version of the Quality of Life Scale (QOLS-N) [2019]. The QOLS contains 16 items that measure material and physical well-being; relationships with other people; social, community, and civic activities; personal development and fulfilment; and recreation. Each item is rated on a 7-point scale (1=not satisfied at all, 7=very satisfied). The QOLS-N has been found to be reliable (Cronbach's alpha 0.86-0.89) and valid in stable chronic illness groups and in the general Norwegian population [2019, 210].

The parents' experiences of the family-centeredness of services were assessed with the Measure of Processes of Care (MPOC-20). The MPOC-20 contains 20 items and the following five scales: (1) *Enabling and partnership*; (2) *Providing general information*; (3) *Providing specific information about the child*; (4) *Coordinated and comprehensive care for the family and child*; and (5) *Respectful and supportive care* [221]. The respondents report the degree to which they feel that service providers display family-centred behaviour using a 7-point scale that ranges from "not at all" (score = 1) to "to a very great extent" (score = 7). The MPOC-20 has been translated into Norwegian and has proven to be reliable (ICC 0.78–0.86) and valid [232].

Data collection

The baseline measurements of the primary and secondary outcomes were performed immediately after randomisation, and the follow-up measurements were collected one week prior to the subsequent offered course (four months after baseline) for both groups. In addition, the included children were classified according to the GMFCS [3] and the Manual Ability Classification System (MACS) [243] at baseline and at follow-up. Due to travel distances, three experienced and blinded physiotherapists ~~and assessors~~ conducted the GMFM-66, GMFCS and MACS clinical ~~measurements~~assessments. The first author performed all of the PEDI interviews.

At baseline, all included parents completed a modified Norwegian version of the Parental Account of Children's Symptoms (PACSNO) [254], which has been found to be valid in a Norwegian context. This questionnaire includes information such as the parents' employment and level of education and the child's age, gender, type of CP, and additional CP-related problems (e.g., problems with vision, cognition, respiration, epilepsy, and pain). To capture the characteristics of conventional practice, the parents were reminded to complete the log at the middle of each month and at follow up. In addition, the parents in the waiting list group completed a log on the first week of the CE group course whilst undertaking the conventional program. They reported the target and frequency of training in the last week (appendix). The current paper only presents the data on the target and frequency of training and use of CE-equipment and rhythmical intention from week 2 after baseline for the waiting list group and week 14 after baseline for both groups.

Data analyses

The characteristics of the participants and the conventional practice are presented with descriptive statistics. Differences in the categorical data (such as sex, CP type, functional

level) were investigated using the Fishers' exact test. Differences in the age between the groups were analysed using the Mann-Whitney U-test.

The sample size and power calculation were estimated using the primary outcome, the GMFM-66. The smallest clinically important difference of the GMFM-66 was set at 5 points, and the SD was assumed to be 4.5 for this age group [26~~5~~]. Based on a power of 80%, an alpha of 0.05 and the above-mentioned assumption, a total of 22 participants were required for this trial. Changes in the GMFM-66 total score are presented as the mean and SD of the difference between the baseline score and follow-up score (4 months later). The difference in changes between the groups is presented as the mean and 95% confidence interval. A two sample t-test was run to detect differences between the two study groups in the mean change. Due to the small sample size, non-parametric sensitivity analyses were performed using Mann-Whitney U-tests to verify the conclusion from the two sample t-tests. To investigate the change from baseline to follow-up within the groups, Wilcoxon Signed ranks tests were performed separately for each study group. For all analyses, a p-value < 0.05 was regarded as statistically significant. All analyses were performed according to the intention-to-treat principle based on the available cases. We did not impute values for missing data. All analyses were performed using IBM SPSS Statistics 20.

Results

Flow of participants

Twenty-one children participated in this study (Figure 1). Of these children, one dropped out due to a serious illness in the immediate family. The characteristics of the participating children and parents are analysed in Table 1. There were no statistically significant differences in any child or parent characteristics between the two groups.

Descriptive data of conventional practice

The parent-reported log at week 14 showed that at least two-thirds of the children in both groups performed motor function and functional skills training at least three times per week (typically daily to several times per day) (Table 2). About half of the participating parents reported involvement in the conventional practicing at home (not reported in table 2).

Short-term between-group differences

After four months, no statistically significant difference in the primary outcome, GMFM-66, (mean difference -1.55 (95% CI -4.69, 1.56), p=0.31)) was established between the CE group and the waiting list group (Table 3). The sensitivity analysis (Mann-Whitney U-test) supported this result. In addition, no significant differences in the secondary outcomes, PEDI or PedsQL, were established between the two groups (Table 3).

For the parent-related secondary outcomes, no differences in QOLS were established. Two significant differences in the MPOC-20 were found between the groups. First, at follow-up, parents in the CE group reported higher scores on "Enabling and partnership" (scale 1) than those in the waiting list group (mean difference -1.32 (95% CI -2.62, -0.02), p=0.05)). However, a statistically non-significant difference was found in the non-parametric sensitivity analysis. Second, parents in the CE group reported higher scores on "Providing specific information about the child" (scale 3) than the parents in the waiting list group (mean difference -1.52 (95% CI -2.69, -0.35), p=0.01)). This difference was replicated in the sensitivity analysis.

Short-term changes within the groups

The GMFM-66 mean change score was 2.89 (SD 2.52) in the CE group, whereas the mean change score of the waiting list group was 1.33 (SD 3.93). The mean change scores of PEDI and PedsQL showed small, non-significant changes (Table 3).

The mean change scores of the MPOC-20 and QOLS are presented in Table 4.
The Wilcoxon signed ranks test demonstrated a significant decrease in the QOLS (p=0.01) in the CE group and a non-significant decrease in these scores in the waiting list group (p=0.59). Moreover, the Wilcoxon Signed ranks test found no significant within-group change in the MPOC-20 scale 1, "Enabling and partnership," in the CE group (p=0.28) or the waiting list group (p=0.13). However, in terms of the MPOC-20 scale 3, "Specific information about the child," the waiting list group (p=0.02) demonstrated a significant decrease in scores from baseline to follow-up, and the CE group (p=0.09) demonstrated a non-significant increase in scores. These changes in scores resulted in an established difference between the groups (as reported above).

Discussion

This randomised controlled trial did not identify additional improvements in the primary outcome of gross motor function in the CE group compared to the waiting list group after four months. Furthermore, no additional improvements in the secondary child-related outcomes of functional skills and health-related quality of life were identified. Only one difference in the secondary parent-related outcomes was found between the study groups. At four months follow-up, the parents in the CE group experienced more "specific information about their child" than parents in the waiting list group. The parents in both groups reported a large amount of conventional practice in the web-based log at week 14, potentially explaining the lack of additional effects of the CE course.

Other studies that have compared CE to conventional rehabilitation or another intensive training program have also failed to establish group differences in motor function and functional skills in samples of young children with CP [276, 287]. These studies do not indicate that CE is ineffective. Rather, they indicate that CE does not seem to be more effective than other interventions.

To our knowledge, the present large amount of parent-reported conventional practice has only been identified in three other studies [8-10]. In the two Norwegian studies [8, 9], the training was often incorporated into daily activities at home and in the kindergarten, whereas in Ødman and Øberg [10], the context of training was not reported. As children with CP need a large amount of practice to acquire motor and functional skills [298], home training is often found in the intensive training of young children [2]. In addition, all young children, including children with CP, develop basic motor functions and learn a variety of functional skills [3029]. Therefore, this large amount of conventional practice might indicate that families adapt situations and encourage the young child to practice everyday activities at home to acquire functional skills.

The current results showed a mean change of 2.89 in the GMFM-66 score in the CE group and of 1.33 in the waiting list group at four months (Table 3). These results are below the set smallest clinically important difference of 5 points and the SD of 4.5 on the GMFM-66 [265], which affected both the sample size calculation and the power analysis for this study. Therefore the results cannot be interpreted as an improvement. However, children with CP have, on average, reached 90% of their gross motor capability at the age of 5 years (and even earlier for children at GMFCS level IV-V) [310]. In a non-randomised controlled trial [10],

which identified a large amount of conventional practice, limited added effects of CE on the GMFM-88 and that the children seemed to function close to their optimal level. Considering the median age of 4 years in the current study and that half of the participating children had GFMCS level IV and V, a majority of the children might already have reached their gross motor developmental potential through the large amount of conventional practice. This consideration, might contribute to explain the small changes that the CE added to gross motor function.

No or small improvements in the functional skills scales of the PEDI were identified in both groups (Table 3) at four months. Due to CE's focus on everyday skills and the group setting, it might be reasonable to expect a greater improvement in self-care, mobility and social skills in the CE group. However, the current finding is consistent with other controlled trials of CE among young children with CP [276, 287].

At four months follow-up, the parents in the CE group reported having received more specific information about their child than the waiting list group (MPOC-20-scale 3). In the CE course, there are many opportunities for formal and informal meetings with the CE-conductor to discuss the child's development and the treatment. By contrast, parents have reported limitations in information sharing behaviour in the primary health-care setting [321]. This might suggest that it is easier to satisfy the parents' information needs, than to improve the child's functional skills.

The small sample size might have weakened the internal and external validity of this study. As opposed to other countries the CE-treatment is run as three week courses in Norway. It is not known whether longer training periods could have changed the results. Due to few eligible

participants and long travel distances, three GMFM-66 assessors were necessary. They were all experienced assessors, but inter-rater agreement was not assessed.

Conclusion

No significant differences in gross motor function, functional skills, children's health-related and parents' global quality of life, and small differences in parents' experiences of family-centred services were identified between the CE group and the waiting list group at four months follow-up. The large amount of parent-reported conventional practice in the log might explain why no added effects of a three week CE were identified. Only one group difference was established. The parents in the CE group reported that they had received more specific information about the child than parents in the waiting list group. This underlines the importance of a close dialogue and sufficient information to the parents about the child's condition and development. However, all the results must be interpreted with caution due to the small sample size.

Acknowledgement

This study would not have been possible without the participating children and parents, to whom we owe great gratitude and respect. Special thanks go to [redacted], who conducted the clinical measurements of motor function (GMFM-66, GMFCS, and MACS). Thanks go to [redacted], who made the randomisation list and acted as the randomisation central, and [redacted], who made the log and was in charge of the database. Without the cooperation and support of [redacted], this study would not have been realised. Last, we would like to thank [redacted] for

their methodological support in the planning of this study. [redacted]

Declaration of interests: The authors report no declarations of interest. The authors alone are responsible for the content and writing of this article.

Appendix

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TABLE 1. Characteristics of the included participants at baseline

TABLE 2. Parent-reported conventional practice

TABLE 3. Results for the child-related outcomes

TABLE 4. Results for the parent-related outcomes

Figure 1. Flow diagram

TABLE 1. Characteristics of the included participants at baseline

Characteristics of the included participants	CE group	Waiting list group	P-value
Children	11	10	
Sex, n			0.39[a]
Female	6	3	
Male	5	7	
Age, median	4	4	0.94[b]
Interquartile range	3-4.5	3-4	
CP type, n			0.18[a]
Spastic, unilateral	6	6	
bilateral	1	3	
Dyskinetic	3	0	
Ataxic	1	0	
Unclassified CP	0	1	
GMFCS level, n			0.69[a]
I	3	2	
II	0	2	
III	3	1	
IV	2	2	
V	3	3	
MACS level, n			0.28[a]
I	3	0	
II	3	5	
III	2	1	
IV	0	2	
V	3	2	
Additional CP-related problems, n			0.64[a]
≤5	6	3	
>5	4	5	
Parents			
Mother's education, n			0.06[a]
≤12 yr (less than high school or high school)	1	5	
>12 yr (college or university)	10	5	
Father's education, n			0.18[a]
≤12 yr (less than high school or high school)	3	6	
>12 yr (college or university)	8	3	

[a]analysed with Fishers' exact test, [b]analysed with Mann-Whitney U-test

TABLE 2. Parent-reported conventional practice

Targets, amount and content of training	2nd week parent-reported conventional practice Waiting list group, (n=9)	14th week parent-reported conventional practice CE group (n=11)	14th week parent-reported conventional practice Waiting list group, (n=8)
Gross motor function			
<3[a] times per week	3	2	2
3-6 times per week	0	0	0
Every day	2	4	1
Several times per day	4	5	5
Hand function			
<3[a] times per week	3	2	1
3-6 times per week	2	1	1
Every day	2	6	3
Several times per day	2	2	3
Eating & drinking			
<3[a] times per week	0	0	0
3-6 times per week	0	0	0
Every day	3	3	2
Several times per day	6	8	6
Getting dressed			
<3[a] times per week	3	3	3
3-6 times per week	0	0	0
Every day	4	4	4
Several times per day	2	4	1
Communication			
<3[a] times per week	2	3	0
3-6 times per week	0	2	0
Every day	4	3	5
Several times per day	3	3	3
Playing skills			
<3[a] times per week	2	0	1
3-6 times per week	1	5	1
Every day	3	3	5
Several times per day	3	3	1
Social skills			
<3[a] times per week	1	1	0
3-6 times per week	2	2	2
Every day	3	5	5
Several times per day	3	3	1
Rhythmical intentions			
<3[a] times per week		10	8[b]
3-6 times per week		1	0
Every day		0	0
Several times per		0	0

day		
CE-equipment (e.g., ladder back chair)		
<3[a] times per week	10	8[b]
3-6 times per week	1	0
Every day	0	0
Several times per day	0	0

[a]Includes none, 1-2 times per week and do not know, [b]All the 8 parents reported none

TABLE 3. Results for the child-related outcomes

Outcomes	Study groups	Baseline			Mean change score			Differences in mean change (MD) score between groups at four months[c]		
		n	Mean	SD	n	Mean change score	SD	MD	95% CI	p-value
GMFM-66[a] total	CE group	11	49.23	20.34	11	2.89	2.52			
	Waiting list group	10	50.28	24.41	8	1.33	3.93	-1.55	-4.67, 1.56	0.31

[a]scaled score range 0-100 (higher score indicates better functioning), [b]0=never, 5=almost always (higher score indicates more problems), [c] analysed using two sample t-test

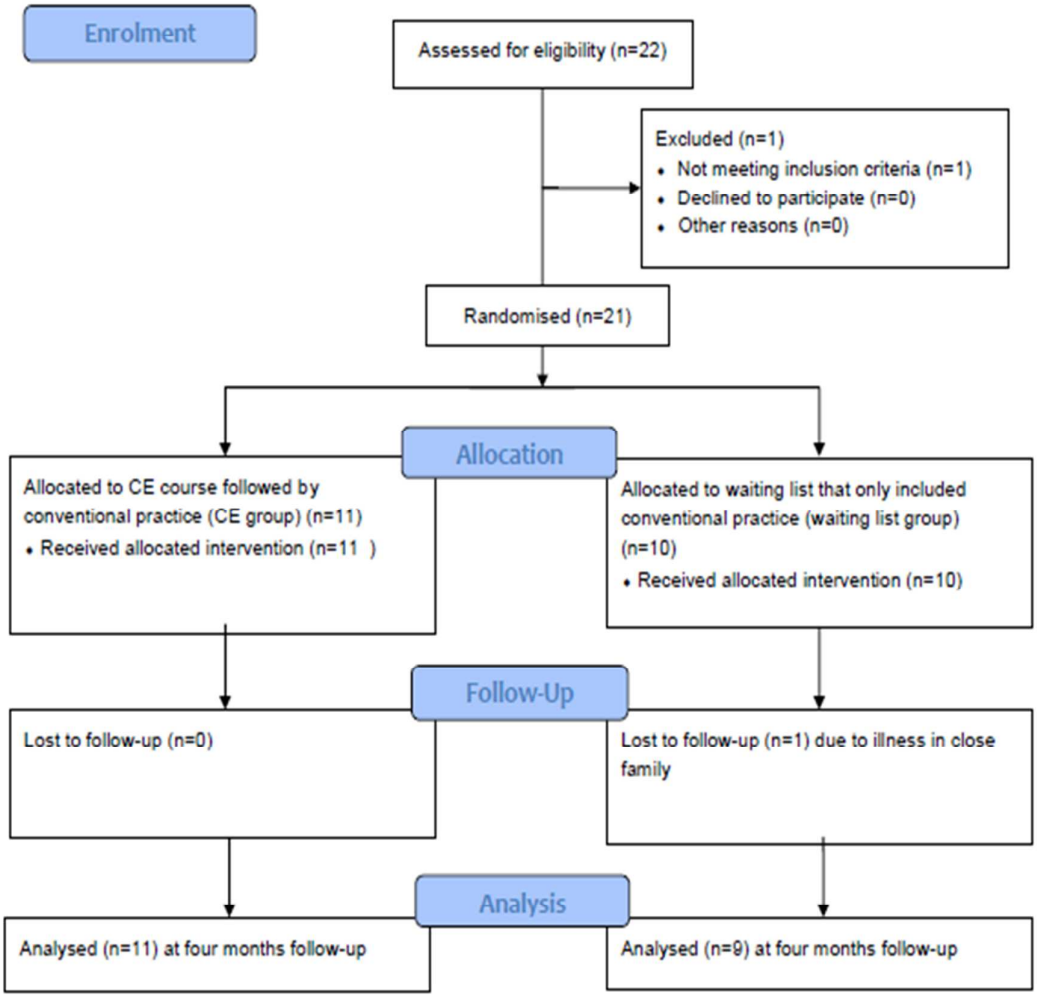
PEDI[a], self-care scale	CE group	11	48.25	11.28	11	2.23	3.42			
	Waiting list group	10	44.62	13.03	9	0.66	4.14	-1.57	-5.12, 1.98	0.37
PEDI[a], mobility scale	CE group	11	48.16	23.61	11	3.30	5.64			
	Waiting list group	10	46.52	19.38	9	-0.01	7.42	-3.31	-9.45, 2.82	0.27
PEDI[a], social function scale	CE group	11	56.49	6.26	11	1.33	1.91			
	Waiting list group	10	50.91	10.04	9	-0.43	3.30	-1.76	-4.24, 0.72	0.15
PedsQL[b], physical functioning scale	CE group	11	2.27	1.18	10	-0.05	0.96			
	Waiting list group	10	2.49	0.74	9	-0.10	0.48	-0.05	-0.80, 0.70	0.89
PedsQL[b], emotional functioning scale	CE group	11	1.22	0.61	10	0.16	0.54			
	Waiting list group	10	1.18	0.55	9	-0.13	0.28	-0.29	-0.72, 0.13	0.16
PedsQL[b], social functioning scale	CE group	11	2.13	0.74	10	0.08	0.49			
	Waiting list group	10	1.88	0.61	9	-0.09	0.30	-0.17	-0.57, 0.23	0.39
PedsQL[b], functioning in kindergarten scale	CE group	11	1.63	0.78	10	-0.18	0.66			
	Waiting list group	9	1.78	0.47	7	0.15	0.18	0.32	-0.23, 0.87	0.23

TABLE 4. Results for the parent-related outcomes

Outcomes	Study groups	Baseline			Mean change score				Differences in mean change (MD) score between groups at four months[d]		
		n	Mean score	SD	n	Mean change score	SD	p-value[c]	MD	95% CI	p-value
QOLS[a] total	CE group	11	84.00	13.27	11	-10.09	12.35	0.01			
	Waiting list group	10	82.50	12.60	8	-1.50	13.48	0.59	8.59	-3.98, 21.17	0.17
MPOC-20[b], scale 1 (Enabling and partnership)	CE group	11	3.85	1.30	11	0.39	1.41	0.28			
	Waiting list group	10	3.96	1.60	9	-0.92	1.34	0.13	-1.32	-2.62, -0.02	0.05
MPOC-20, scale 2 (Providing general information)	CE group	11	2.76	1.51	11	-0.20	1.77				
	Waiting list group	10	3.26	1.56	9	-0.02	0.99		0.18	-1.21, 1.57	0.79
MPOC-20, scale 3 (Providing specific information about the child)	CE group	11	4.45	1.42	11	0.72	1.53	0.09			
	Waiting list group	10	4.20	1.52	9	-0.79	0.71	0.02	-1.52	-2.69, -0.35	0.01
MPOC-20, scale 4, (Coordinated and comprehensive care)	CE group	11	4.91	1.02	11	-0.41	1.16				
	Waiting list group	10	4.45	1.41	9	0.22	1.54		0.63	-0.64, 1.90	0.31
MPOC-20, scale 5, (Respectful and supportive care)	CE group	11	4.82	0.73	11	0.28	0.62				
	Waiting list group	10	4.73	0.95	9	0.31	0.79		0.03	-0.64, 0.69	0.93

[a]QOLS score 1=not satisfied at all, 7=very satisfied; [b]MPOC-20 Score 0 = not applicable; 1 = does not happen at all; 2 = happens to a very small extent; 3 = happens to a small extent; 4 = happens to some extent; 5 = happens to a fairly great extent; 6 = happens to a great extent; 7 = happens to a very great extent; [c]analysed using Wilcoxon Signed Rank test,[d] analysed using two sample t-test

FIGURE 1. Flow Diagram



Questions in the log

Welcome to log training and other rehabilitation interventions in the PTØ-study!

We ask you to fill in this log once every month as long as your child is included in the PTØ-study. The aim of this log is to gain more knowledge about what type of training and other rehabilitation interventions your child have performed/received, between the CE courses or at the waiting list. When your child is at the CE course, you are not supposed to fill in the log.

Please log all training performed at home, in the kindergarten, at the physiotherapy centre or in other places.

Please tick off the relevant option.

Question 1. How many times has your child performed gross motor training (e.g., lifting up the head, sitting, walking and standing) the last week? Only one option is available.

1. None
2. 1-2 times per week
3. 3-6 times per week
4. Every day
5. Several times per day
6. Do not know

Question 2. Who has trained the child? Several options are available.

1. The parents
2. Assistant
3. Preschool teacher/special educator
4. Physiotherapist
5. Other
6. Do not know

Question 3. How many times has your child performed fine motor training (e.g., grasping, releasing, cutting, threading beads, drawing) the last week? Only one option is available.

1. None

2. 1-2 times per week
3. 3-6 times per week
4. Every day
5. Several times per day
6. Do not know

Question 4. Who has trained the child? Several options are available.

1. The parents
2. Assistant
3. Preschool teacher/special educator
4. Occupational therapist
5. Physiotherapist
6. Others
7. Do not know

Question 5. How many times has your child performed language and speech training (e.g., sounds, words, naming things, sing, ask for something) the last week? Only one option is available.

1. None
2. 1-2 times per week
3. 3-6 times per week
4. Every day
5. Several times per day
6. Do not know

Question 6. Has your child performed alternative communication training (e.g., sign language, use of photos, pictogram, and voice machine) the last week?

1. Yes
2. No

Question 7. Who has trained the child? Several options are available.

1. Parents
2. Other family members
3. Assistant
4. Preschool teacher/special educator
5. Occupational therapist
6. Others
7. Do not know

Question 8. How many times has your child performed training on eating and drinking the last week? Only one option is available.

1. None
2. 1-2 times per week
3. 3-6 times per week
4. Every day
5. Several times per day
6. Do not know

Question 9. Who has trained the child? Several options are available.

1. Parents
2. Other family members
3. Assistant
4. Occupational therapist
5. Physiotherapist
6. Others
7. Do not know

Question 10. How many times has your child performed training of getting dressed and undressed the last week? Only one option is available.

1. None

2. 1-2 times per week
3. 3-6 times per week
4. Every day
5. Several times per day
6. Do not know

Question 11. Who has trained the child? Several options are available.

1. Parents
2. Other family members
3. Assistant
4. Occupational therapist
5. Physiotherapist
6. Preschool teacher/special educator
7. Others
8. Do not know

Question 12. How many times has your child performed training on playing skills (e.g., building, puzzles, playing with dolls, role-play) the last week? Only one option is available.

1. None
2. 1-2 times per week
3. 3-6 times per week
4. Every day
5. Several times per day
6. Do not know

Question 13. Who has trained the child? Several options are available.

1. Parents
2. Other family members
3. Assistant

4. Preschool teacher/special educator
5. Occupational therapist
6. Others
7. Do not know

Question 14. How many times has your child performed training of social skills (e.g., played with children or adults, participated in conversations) the last week? Only one option is available.

1. None
2. 1-2 times per week
3. 3-6 times per week
4. Every day
5. Several times per day
6. Do not know

Question 15. Who has trained the child? Several options are available.

1. Parents
2. Other family members
3. Assistant
4. Preschool teacher/special educator
5. Others
6. Do not know

Question 16. How many times has your child participated in physical activities (e.g., swimming, riding, sledding, biking)? Only one option is available.

1. None
2. 1-2 times per week
3. 3-6 times per week
4. Every day
5. Several times per day

6. Do not know

Question 17. Have you participated in parent education, attended courses or received other parent training the last week?

1. No
2. Yes.

Question 18. What was the topic of the parent training?
…….(please write here)

Question 19. Which professionals or agencies have you been in contact with the last week? Several options are available.

1. Physiotherapist
2. Special educator
3. Occupational therapist
4. Medical doctor
5. Psychologist
6. Personal coordinator (multidisciplinary team/individual plan)
7. Norwegian labour and welfare administration (NAV)
8. Paediatric rehabilitation service
9. Others, whom…

Only answer the next questions after you have attended a CE course

Question 20. How often has your child used CE-equipments (e.g., slatted wooden tables, ladder-back chairs) the last week? Only one option is available.

1. None
2. 1-2 times per week
3. 3-6 times per week
4. Every day
5. Several times per day
6. Do not know

Question 21. How often have you used song, rhythm, or rhyme the last week that your child has learned on a CE course? Only one option is available.

1. None
2. 1-2 times per week
3. 3-6 times per week
4. Every day
5. Several times per day
6. Do not know

Question 22: Do you have any other information about your child's training or rehabilitation interventions the last week that you want to describe?

……(please write here)

Thank you for completing the log!