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## Process Evaluation of Home-based Bimanual Training in Children with Unilateral Cerebral Palsy (The COAD-study): A Mixed Methods Study

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### ABSTRACT

**Purpose:** To evaluate the processes and factors that influenced implementation and impact of a home-based bimanual training program in children with unilateral cerebral palsy aged 2 through 7 years.

**Methods:** The program encompassed bimanual task-specific training (3.5 hours/week for 12 weeks) adopting either implicit or explicit motor learning. A therapist and remedial educationalist coached parents. This mixed methods study included course attendance monitoring, questionnaires, registration form, video analysis, interviews, focus group discussion, and drop-out monitoring.

**Results:** Fourteen families participated. The program was not fully implemented as intended. Parents positively experienced the training and were well able to provide it. The program was demanding for the children and time-consuming for parents. Several components positively contributed to the program: task-analysis, instructional videos, and coaching by a therapist and remedial educationalist. Several modifications to the program were proposed.

**Conclusion:** Home-based bimanual training forms a demanding but promising therapeutic approach with potential for optimization.

### ARTICLE HISTORY

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### KEYWORDS

Cerebral palsy; upper extremity; home-based training; bimanual training; process evaluation

## Introduction

### Home-based Training in Cerebral Palsy (CP)

Unilateral cerebral palsy (uCP) is characterized by impairments in bimanual performance.<sup>1</sup> There is robust evidence that bimanual intensive movement therapy results in meaningful improvements of bimanual coordination, bilateral spontaneous hand use, and activities that are relevant for the child.<sup>2–4</sup> However, it is of great importance that learning is generalized to the natural environment where the child eventually has to perform bimanual activities, become independent, and participate in society.<sup>5</sup> Practice in the home setting meets this requirement of practice specificity and optimizes transfer of learning, which is a great advantage compared to center-based treatment. Parent-delivered training at home also complies with principles of family-centered care,<sup>6</sup> and may increase self-efficacy, empowerment, and self-reliance of parents.

Several reviews showed that home-based programs can be effective in improving clinical outcomes.<sup>2,7,8</sup> However, studies are mostly incomplete in describing the intervention protocol, especially in terms of motor learning principles and coaching approaches.<sup>8</sup> A common distinction is made between implicit and explicit techniques, of which various definitions exist. Based on a Delphi study, Kleynen et al.<sup>9</sup> define implicit motor learning as “learning which progresses with no or

minimal increase in verbal knowledge of movement performance (e.g. facts and rules) and without awareness.” Explicit motor learning on the other hand is considered to be “learning which generates verbal knowledge of movement performance (e.g. facts and rules), involves cognitive stages within the learning process, and is dependent on working memory involvement”.<sup>9</sup> While these definitions of implicit and explicit motor learning may seem to represent a dichotomy, the current study adopts the widely accepted perspective that they represent tail ends of a motor learning spectrum.<sup>9</sup> Implicit motor learning is less demanding for the working memory,<sup>10</sup> which is relatively often impaired in children with CP.<sup>11</sup> Moreover, it is believed to put less strain on the parent-child interaction when applied in a training program.<sup>12</sup> However, the applicability of both principles for home-based training has not been studied. Existing interventions have also been restricted to monodisciplinary coaching of parents by therapists. While various coaching modes are applied in home-based therapy programs for children with CP (such as training, written or visual instructions, logbook reviews, computer feedback, e-mail, (video) calls, or home visits), evaluation of these approaches has received scant attention in the literature.<sup>8</sup> Ziegler and Hadders-Algra highlight the importance of coaching and of understanding the merits and difficulties of the application of different coaching modes, including documenting details of the

coaching process as well as exploring parents' experiences with it.<sup>13</sup> In conclusion, more research is needed on bimanual training in the home environment and on the multiplicity of components in home programs.

### **Intervention**

Within the COAD-study (CO-creation At hand: the road to independence), a home-based bimanual training program has been developed, targeting young children with uCP.<sup>12</sup> The aim of the program is to increase bimanual activity performance of the child, without increasing parental stress. The training is parent-delivered, aided by interdisciplinary coaching by an occupational/physical therapist and a remedial educationalist or health-care psychologist. The latter is involved as it is known that home-based programs can negatively impact parent-child interaction and wellbeing of the family, impeding therapy compliance. Two protocols were adopted: the motor learning approach in one protocol is at the implicit end of the motor learning spectrum, while in the other protocol parents are instructed to use a predominantly explicit motor learning approach.

### **Process Evaluation**

Rehabilitation interventions are complex, involving a process that includes numerous actions, and are carried out in complex environments.<sup>14</sup> A major challenge in rehabilitation research is to evaluate the interacting intervention components as a whole. For this reason, Wade et al. recommend a process evaluation of interventions delivered in studies.<sup>14</sup> The delivery of training by parents and the collaboration between parents and health-care professionals further complicate home-based training programs. Nonetheless, a systematic review revealed that studies thus far have not performed a comprehensive process evaluation, but only examined compliance with and acceptability of the prescribed home-based training. These evaluations were related to the overall programs, but did not provide an assessment of specific aspects of the home programs.<sup>8</sup> The only study on parent-delivered bimanual training found good adherence to treatment protocols, high compliance with the functional and playful child-friendly games, and positive parent perceptions.<sup>15</sup> It is intended that the current research will contribute to a deeper understanding of parent-delivered home-based bimanual training programs.

### **Mixed Methods Design**

The current paper reports on the outcomes of the process evaluation. In a separately published case series, the effect of the home-based training was evaluated.<sup>16</sup> The COAD-study as well as its process evaluation adopted a mixed methods methodology, which can be defined as "... research in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry."<sup>17</sup> The design is highly appropriate for comprehending processes and explanation of quantitative findings by qualitative data. Advantages of the mixed methods design include, but are not limited to, high validity due to

triangulation of quantitative and qualitative methods as well as counterbalancing the individual methods' weaknesses.<sup>18</sup> In the process evaluation, the quantitative strand included objective and basic information. In-depth experiences were appraised by qualitative data collection. Conclusions were drawn from the meta-inference of the quantitative and qualitative data.

### **Objectives of This Study**

The aim of the current study was to evaluate the processes and factors that influenced implementation and impact of the program. Four main research questions guided the process evaluation:

- (1) To what extent was the home-based training program implemented as intended?
- (2) How did parents experience the home-based training program and how did they integrate the program into family life?
- (3) Which components of the home-based training program contributed to the impact of the program?
- (4) What contextual factors with regard to children, parents, and health-care professionals were associated with possible variation in implementation and outcomes between child:parents:health-care professionals triads?

## **Materials and Methods**

### **Design and Paradigm**

In this mixed methods study, a concurrent embedded experimental design was utilized: the mainly qualitative process evaluation was embedded in the quantitative experimental design. Qualitative and quantitative data of the process evaluation had equal priority and were gathered longitudinally throughout the same period. The qualitative and quantitative strands had an interactive relationship and were primarily mixed at the level of design and interpretation. A pragmatic worldview guided this study. This paradigm addresses the consequences of research, is problem-centered, pluralistic, and real-world-practice oriented.<sup>18</sup> A generic qualitative approach was applied to the qualitative strand.<sup>19</sup> The full protocol of the process evaluation has been described elsewhere.<sup>20</sup>

### **Participants**

A total population sample of the effect study participants was included in the process evaluation. Participants were recruited from five rehabilitation centers on seven locations across urban as well as rural areas in the Netherlands between April 2016 and March 2018. This comprised children with uCP, aged 2 through 7 years with Manual Ability Classification System (MACS) Levels I–III,<sup>21</sup> together with their parents.

In addition to the families, the health-care professionals involved in the interventions participated in the process evaluation. Apart from being employed as a physical or occupational therapist, remedial educationalist, or health-care psychologist in one of the collaborating rehabilitation centers, no eligibility criteria were applied.

Ethical approval for the study was granted by the medical ethical committee ‘Commissie Mensgebonden Onderzoek regio Arnhem – Nijmegen’ (NL53670.091.15). Written informed consent was obtained from all participating parents and the legal guardians of participating children. Participants gave permission for audio (and video) recordings. Confidentiality was ensured by the removal of all identifying information.

### **Intervention**

The intervention under study was a home-based bimanual training program, of which the detailed protocols have previously been published.<sup>12</sup> The home-based training program encompassed bimanual task-specific training delivered by the parents, intending to improve the child’s performance of bimanual activities, without inducing therapy-related parental stress. A pediatric physical or occupational therapist (referred to as therapist) and a remedial educationalist or health-care psychologist (referred to as remedial educationalist) from the child’s rehabilitation center jointly coached parents. The professionals attended an instructional course and received a manual so that they might become acquainted with the home-based training protocols before they started coaching. Each therapist was engaged with one of the protocols, whereas the remedial educationalists were involved in both. The entire home-based training program lasted 14 weeks, comprising a two-week preparation phase followed by a 12-week home-based training phase.

### **Preparation Phase**

Parents identified five rehabilitation needs for their child (i.e. bimanual activities) during the administration of the COPM by an independent therapist.<sup>22</sup> Thereafter, an introductory meeting between the parents and the coaching therapist took place at the rehabilitation center, including observation of the child’s bimanual functioning, as well as a meeting between the parents and the remedial educationalist to explain the involvement of the remedial educationalist and to examine the child, parent, and family conditions. Next, the therapist conducted a task analysis for the five target bimanual activities and developed an individualized training plan. In the explicit protocol, the task analysis was complemented by a movement analysis. Further, in both protocols parents prepared themselves by means of watching instructional videos and reading a manual. A home visit by the therapist to assess and discuss the specific home and family situation concluded the preparation phase.

### **Home-based Training Phase**

The aim of the home-based training was for the child to accomplish the five personal goals. Hence, the program adopted a goal-oriented, task-specific approach of bimanual training. Children practiced the five bimanual activities (e.g. closing the zipper of a jacket), preferably in meaningful situations for the child and integrated in his or her daily routines. The training was parent-delivered in the home environment and scheduled for 3.5 hours per week.

Parents gave task-oriented and result-oriented instructions and feedback to the child in both protocols (e.g. ‘please close the zipper all the way up’). The explicit protocol was characterized by additional instructions and feedback focused on the motor performance (e.g. ‘now hold the bottom of the jacket more firmly’), while in the implicit protocol the organization of the activities elicited the targeted motor performance (e.g. zipper length appropriate for the child’s ability).<sup>12</sup>

Parents registered the dose and specifics of training, and video-recorded a training moment each week. Initially, the communication tool ‘Quli’ was provided to parents to share these data with the health-care professionals. When practical issues emerged that impeded the process, the tool ‘arQive’ was implemented instead. The interdisciplinary remote coaching comprised weekly telephone appointments with the therapist, two home visits by the therapist (at four and eight weeks after the start of the training), one standard telephone appointment with the remedial educationalist (after two weeks), and additional consultation with the remedial educationalist if required.

### **Follow-up**

Children received 12 weeks of usual care following the home-based training program.

### **Data Collection**

The components fidelity, dose, recruitment, and context were appraised, as represented in the guide for process evaluations by Saunders et al.<sup>23</sup> The data collection approaches are presented in Table 1 and included course attendance monitoring, questionnaires, a registration form, video analysis, interviews, focus group discussion, and drop-out monitoring. The parent most involved in the training (i.e. ‘primary trainer’) participated in the parent-related procedures.

### **Course Attendance Monitoring**

Attendance at the instructional course for therapists and remedial educationalists was monitored by the research team.

### **Questionnaires**

The evaluation contained three different semi-structured questionnaires. First, the instructors (i.e. research team members) completed a questionnaire regarding the content and procedures applied during the instructional course for therapists and remedial educationalists. Second, the therapist described the conduct of the first home visit for each participant by a questionnaire. Third, both the therapist and remedial educationalist completed a questionnaire for each participant at the end of the home-based training program to evaluate its execution.

### **Registration Form**

In a registration form, parents logged the amount of time spent on training each treatment goal, including any relevant details, as well as the emotions experienced by themselves and observed in their child due to the training.

Table 1. Data collection overview.

Time period	Data collection	Participants	Methodology	Fidelity	Process evaluation components			
					Dose delivered	Dose received (exposure)	Dose received (satisfaction)	Recruitment
Instructional course for therapists and remedial educationalists	Attendance monitoring Questionnaire (n = 22)	n.a. Instructors (n = 4) of 16 courses*	QUAN QUAN + QUAL	X	X			X
	Questionnaire (n = 14) Registration form (n = 11) Video analysis (n = 136) Interviews (n = 22) Questionnaire (n = 28)	Therapists (n = 14) Parents (n = 11) Parents (n = 12) Parents (n = 12) Therapists (n = 14) and remedial educationalists (n = 14)	QUAN + QUAL QUAN QUAN QUAL quan + QUAL	X X X X X		X		X X X
Follow-up Overall home-based training program	Interview (n = 11) Focus group discussion (n = 3)	Parents (n = 11) Therapists (n = 7) and remedial educationalists (n = 3)**	QUAL QUAL	X X		X X		X X
	Drop-out monitoring	n.a.	QUAN + qual					X

n.a.: not applicable; quan: quantitative; qual: qualitative; capitalization represents the dominant strand

\* 4 initial courses and 1 refresher course for therapists coaching in the implicit protocol, 5 initial courses and 1 refresher course for therapists coaching in the explicit protocol, 5 initial courses for remedial educationalists

\*\* 3 therapists and 1 remedial educationalist who participated in the focus group discussions performed a member check

## Video Analysis

Blinded raters (JB and YJ) scored the weekly video recordings of the training for the type of instruction and feedback used by parents. An observational rating tool, consisting of concrete and observable behavioral elements, was applied using a 10-second partial interval time sampling procedure. For each interval the raters scored either category T (task-oriented and result-oriented instruction and feedback), category M (instruction and feedback focused on motor performance), category MT (task-oriented and result-oriented instruction and feedback as well as instruction and feedback focused on motor performance), or category N (no scorable behavior). The percentage of scorable intervals that included task-oriented and/or result-oriented instruction or feedback was calculated. In the same way, the percentage of scorable intervals that included instruction or feedback focused on motor performance was calculated. Before the video analysis, the raters scored and discussed training videos until they and the first author (LB) mutually agreed that there was sufficient consensus in scoring. It was intended to analyze six randomly selected videos per child. However, since the complications with the data sharing tool resulted in a large number of missing videos, all available videos were scored. Twenty percent of the videos were scored in duplicate and independently in order to assess inter-rater reliability (kappa) of the interval scoring.

## Interviews

Following the longitudinal methodology, parents were interviewed repeatedly: halfway through the home-based training phase; at the end of the home-based training; and at the end of the 12-week follow-up. The aim of the interviews was to evaluate the parents' experiences with the home-based training program and the integration of the program in the context of their family life, including a descriptive inventory of perceived therapy-related parental stress. In consultation with an independent peer reviewer (BP), the research team developed a protocol to guide the semi-structured interviews. A trained interviewer (LB) conducted and audiotaped the interviews, the first time at the parents' home and twice by phone or video call.

## Focus Group Discussion

After the closure of inclusion, a convenience sample of therapists and remedial educationalists reflected on the home-based training program during focus group discussions. The remedial educationalists formed one and the therapists two focus groups, independent of the protocol they were involved in. The latter was a minor deviation from the process evaluation protocol, which occurred due to planning issues. A trained researcher (LB) and assistant moderator (MM) guided the focus group discussions, which contained a combination of in-person and simultaneous online/telephone sessions. The focus group discussions followed a protocol and were audio- (and video)taped.

## Drop-out Monitoring

Drop-out rates and reasons were registered for each home-based training protocol.

**Table 2.** Participant characteristics.

Child characteristics (n = 14)		n	%
Protocol	Implicit	5	36
	Explicit	9	64
Gender	Male	11	79
	Female	3	21
Age (years)	2	3	21
	3	3	21
	4	5	36
	5	1	7
	6	1	7
	7	1	7
MACS level	I	1	7
	II	6	43
	III	1	7
	Not applicable*	6	43
GMFCS level	I	13	93
	II	1	7
Type of education	Mainstream nursery school or day-care	4	29
	Therapeutic toddler group	1	7
	Mainstream primary school	5	36
	School for physically disabled children	2	14
	Not applicable	1	7
	Missing value	1	7
Siblings	1	9	64
	2	2	14
	None	3	21
Caregiver characteristics of the primary trainer (n = 14)		n	%
Gender	Male	1	7
	Female	13	93
Relationship to the child	Natural (or adoptive) parent	12	86
	Foster parent	2	14
Family structure	Traditional family	13	93
	Reconstituted family	1	7
Highest education completed	Secondary vocational education	4	29
	Senior general secondary education/pre-university education	1	7
	Higher professional education	7	50
	University education	2	14
Working hours per week	0	2	14
	10–20	2	14
	20–30	7	50
	30–40	3	21
Another family member requiring special care or attention	Yes	2	14
	No	12	86
Caregiver characteristics of the secondary trainer (n = 13)		n	%
Gender	Male	10	77
	Female	3	23
Relationship to the child	Natural (or adoptive) parent	11	85
	Foster parent	1	8
	Grandparent	1	8
Family structure	Traditional family	12	92
	Single-parent family	1	8
Highest education completed	Pre-vocational secondary education	1	8
	Secondary vocational education	6	46
	Higher professional education	5	38
	University education	1	8
Number of working hours per week	10–20	1	8
	20–30	3	21
	30–40	6	46
	>40	3	21

MACS: Manual Ability Classification System; GMFCS: Gross Motor Function Classification System; \* MACS is not validated for children < 4 years of age. For younger included children, the rehabilitation team judged that manual ability was comparable to MACS Level I–III.

### Data Analysis

The quantitative data were analyzed using descriptive statistics. Analysis of the qualitative data was carried out by thematic analysis as reported by Braun and Clarke.<sup>24,25</sup> The consecutive phases were familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report.<sup>24</sup> Inductive and

latent (i.e. interpretative) approaches were adopted. Two researchers (LB and MM) analyzed the interview transcripts and focus group material, followed by debriefing sessions with an independent researcher (BP). The quantitative and qualitative data were analyzed simultaneously, followed by a side-by-side comparison of the qualitative and quantitative findings. Finally, meta-inferences were drawn.

## Trustworthiness

Several procedures were applied in order to enhance credibility. The evaluation involved between- and across-method triangulation, data sources triangulation, site triangulation, and investigator triangulation. Second, the accuracy of the data was checked throughout and at the end of interviews and focus group discussions by paraphrasing and summarizing. In addition, member checking of the preliminary report was carried out by the health-care professionals who were not able to attend the focus group discussions.

The first author (LB) is a PhD candidate with a background in physical therapy, whereas MM is an experienced research assistant, originally educated as a medical analyst. The researchers attempted to prevent the process evaluation's affecting the delivery of the home-based training program, and to view the evaluation with detachment. Considering the nature of self-evaluation, an independent expert (BP) performed peer review in several stages in order to minimize researcher bias. She is a qualified occupational therapist with a doctoral degree and extensive experience in pediatric rehabilitation and qualitative research. During debriefing sessions, the researchers (LB and MM) and the peer reviewer (BP) discussed their interpretations and perceptions.

## Results

### Sample Characteristics

Fourteen families participated in the process evaluation. Nine performed the explicit protocol and five the implicit protocol. The uneven distribution of participants between the protocols can be explained by the randomized clinical trial (RCT) being terminated early due to recruitment problems and continued as a case series in which allocation to the implicit or explicit protocol followed the parents' preference.<sup>16</sup> The characteristics of the families are provided in Table 2.

Eleven therapists and seven remedial educationalists coached parents. They all participated in the process evaluation. The median time they had been working in pediatric rehabilitation was 15 years (range 5–31 years) and 14 years (range 2–22 years) for therapists and remedial educationalists, respectively. Ten of the therapists (91%) reported previous experience with the coaching role.

**Table 4.** Results video analysis (n = 12).

Child (pseudonym)	Protocol	Videos	Intervals	Scorable intervals	Intervals that included task-oriented and/or result-oriented instruction or feedback	Intervals that included instruction or feedback with regard to motor performance
Mike	Implicit	7	100	71	87.3%	18.3%
Samantha	Implicit	8	52	21	81.0%	19.0%
Noah	Implicit	3	27	15	86.7%	20.0%
Robert	Implicit	13	75	57	86.0%	26.3%
Julia	Explicit	40	585	556	98.2%	19.6%
Emma	Explicit	9	126	123	91.9%	29.3%
Kevin	Explicit	3	53	40	97.5%	37.5%
Ryan	Explicit	2	34	28	71.4%	39.3%
Oliver	Explicit	21	145	130	81.5%	45.4%
Thomas	Explicit	20	75	57	78.9%	47.4%
Alexander	Explicit	1	9	9	100%	55.6%
Christian	Explicit	9	70	34	79.4%	61.8%

**Table 3.** Results registration form (n = 11).

Child (pseudonym)	Protocol	Minimum weekly training duration (minutes)	Maximum weekly training duration (minutes)	Mean weekly training duration (minutes)	Total training duration (hours)
Julia	Explicit	40	165	106	21.2
Thomas	Explicit	80	160	120	24.1
Emma	Explicit	0	172	129	25.8
David	Implicit	0	260	134	26.8
Ryan	Explicit	0	310	160	31.9
Noah	Implicit	0	265	165	33.0
Kevin	Explicit	105	207	178	35.6
Mike	Implicit	2	340	195	39.0
Robert	Implicit	185	216	203	40.5
Oliver	Explicit	178	277	209	41.9
Alexander	Explicit	160	255	211	42.3

## Outcomes

The results of the process evaluation are described consecutively per research question. A total of 21 themes derived from the qualitative analysis: two themes for research question 1, twelve for research question 2, four for research question 3, and three for research question 4.

### Research Question 1: To What Extent Was the Home-based Training Program Implemented as Intended?

For this research question, mainly quantitative results are presented first, followed by the qualitative results.

**Instructional Course.** All therapists and remedial educationalists (100%) attended the instructional course. Each therapist who had coached a family for more than one year after the initial course additionally joined a refresher session. The remedial educationalists deemed a refresher session unnecessary and did not attend it.

The total duration of the initial course for therapists ranged from 2 to 7.5 hours. The refresher courses lasted 70–110 minutes. The total course duration for the remedial educationalists ranged from 1 to 3.75 hours.

**Drop-out Monitoring.** The drop-out monitoring showed that, overall, four out of 18 participants (22%) withdrew from the study (implicit protocol n = 2; explicit protocol n = 2). The drop-out rate declined from 29% (2/7) in the RCT to 18% (2/

**Table 5.** Quantitative results questionnaire evaluation individual programs (n = 14).

Topic therapist questionnaire	Result
<b>Home visits</b>	
1. Participants for which all three home visits took place	43% (6/14)
2. Period between introduction meeting and first home visit (weeks)	Median 2.0 (range 1.0–3.0)
3. Period between start of the training and second home visit (weeks)	Median 5.0 (range 4.0–8.0)
4. Period between start of the training and third home visit (weeks)	Median 11.0 (range 10.0–12.0)
5. Participants for which an extra home visit took place	0% (0/14)

Some participants returned incomplete questionnaires, resulting in missing values.

11) in the case series. All four families discontinued participation because of personal circumstances (e.g. house renovation) that interfered with the home-based training. In two cases, the time demand of the training combined with the home situation appeared to be a limiting factor. In one of these families, an additional reason was that it was a struggle to make the weekly video recordings. In the two other cases, no reasons were mentioned that were related to the intervention.

**Goal Setting.** Therapists questioned whether some goals reflected the child's needs, as the parents defined them. Therapists also reported that, for 23% (3/13) of the children, one or two goals were added to the five predefined goals, while goals were sometimes no longer pursued. Reasons for these changes included the child's success with multiple goals, the arising of new needs, or the child's frustration with an activity.

**Table 6.** Quantitative results report form first home visit (n = 14).

Topic	Minutes the topic was discussed (median (range))	Number of parents who sufficiently understood the topic discussed
<i>Instructional videos</i>		
1. Questions of parents	3.5 (0–10)	n.a.
2. Teaching approach	10.0 (0–75)	100% (12/12)
<i>Home-based training program</i>		
3. Overview of entire 12-week program	10.0 (0–45)	100% (11/11)
4. Coaching approach	7.5 (1–10)	100% (11/11)
5. Plan and teaching approach for the first training week	15.0 (2–60)	100% (10/10)
6. Registration	5.0 (1–10)	80% (8/10)
7. Video recordings	5.0 (0–10)	100% (10/10)
<i>Setting of home-based training</i>		
8. Available training objects	5.0 (3–10)	
9. Training objects brought by the therapist	5.0 (0–15)	
10. Location of training	5.0 (0–10)	
<i>Data sharing system</i>		
11. Setting up data sharing system	5.0 (0–10)	
<i>Registration form</i>		
12. Providing the digital registration form to parents	1.0 (0–10)	

Some participants returned incomplete questionnaires, resulting in missing values.

n.a.: not applicable

**Table 7.** Quantitative results questionnaire evaluation individual programs (n = 14).

Topic remedial educationalist questionnaire	Result
1. Participants for which the telephone appointment took place	77% (10/13)
2. Period between start of the training and telephone appointment (weeks)	Median 2.6 (range 1.3–4.0)
3. Participants for which additional appointments took place	0% (0/14)
4. Participants for which the therapist consulted the remedial educationalist	23% (3/13)

Note: Some participants returned incomplete questionnaires, resulting in missing values.

**Instructional Videos.** Therapists reported that the parents of some children did not watch the instructional videos, or did so only partially.

**Home-based Training.** The median training duration was 12.6 weeks (range 11.0–14.7). With 36% (5/14) of the participants, an interruption, and therefore extension, of the program occurred. Most parents did not comply with the 3.5 hours (210 minutes) of training per week. As can be seen from Table 3, the mean weekly training duration ranged from 106 to 211 minutes (median 165, IQR 67.5). The median training duration amounted to 79% of the intended intensity for the total sample, 86% for the implicit protocol, and 76% for the explicit protocol.

From analysis of available video-recorded training sessions, it was calculated that the average percentage of intervals that included task-oriented and/or result-oriented instruction or feedback was 85.2 (SD 2.9) in the implicit protocol, and 87.4 (SD 10.8) in the explicit protocol. The mean percentage of intervals that included instruction or feedback with regard to motor performance was 20.9 (SD 3.7) in the implicit protocol. In the explicit protocol, this percentage was 42.0 (SD 13.7), twice as high (Table 4). Kappa was 0.54. According to the interpretation guidelines of Landis and Koch,<sup>26</sup> this represents a moderate agreement between the raters.

**Telephone Appointments by Therapist.** Telephone appointments with the therapist took place every week according to protocol in 57% (8/14) of the participants. Therapists commented that telephone appointments were sometimes canceled because it was not a good time for parents or they had forgotten, or for holidays or illness.

**Home Visits by Therapist.** All three home visits with the therapist took place according to protocol in 43% (6/14) of participants. However, therapists might visit families at home at a later time in the program than scheduled (Table 5). During the first home visit, most time was spent on discussing the teaching approach, the program overview, and the plan for the first training week. Except for the registration of the home-based training, therapists had the impression that parents sufficiently understood the topics discussed (Table 6).

**Remedial Educationalist Coaching.** The telephone appointment with the remedial educationalist took place with 77% of parents. Some remedial educationists said that they were



unable to reach the parents by telephone. For 29% of the children, the therapist consulted the remedial educationalist at the start of the program for a specific question. Throughout the program, with 23% of the participants the therapist consulted with the remedial educationalist (Table 7).

**Registration Form.** Two parents (14%) did not complete the digital registration form. Additionally, one parent (7%) provided a hand-written narrative description of the training and one (7%) filled out a different but comparable logbook on paper.

**Sharing of Data.** Only 29% of parents (4/14) and therapists (4/14) used the data sharing system provided to send videos and treatment information, respectively.

**Theme 1.1: Some Protocol Deviations Occurred with Training Intensity, Motor Learning Approach, Task-specificity, Telephone Appointments, and Home Visits.** Families did not always manage to comply with the *training intensity*. Additionally, for some young children it was not always doable to practice for at least ten consecutive minutes, as prescribed in the protocol.

Concerning the *motor learning approach*, parents and therapists stated that they did not always comply with the implicit protocol, since instructions included motor performance elements. Similarly, although the focus was on explicit motor learning, implicit elements were also integrated to some extent in the explicit protocol.

The (focus group) interviews with parents and therapists revealed that for some goals they adopted a looser interpretation. Although the activities practiced were in some way related to the targeted goals, not all training was *task-specific*. This included a range of activities that required the same actions, for instance in the way of holding an object, as in the originally targeted activity (i.e. pudding cup, sandbox toys, or Yahtzee). Another example was given by a parent:

At one point I had that video where she was braiding her hair. And that was just a very cute video, so I forwarded it to the therapist, like: 'yes, it does not match the goals, but I think it is such a nice movie'. And then she said: '[...] of course it belongs to your goals, because that is again, on the basis of tying shoelaces, that is a particular act'. (parent)

These varying activities were chosen in order for parents to attain the practice time and were considered as training by parents as well as therapists.

Sometimes therapists e-mailed instead of *telephone appointments*. Some therapists indicated that the duration of the phone calls fluctuated throughout the program from five to thirty minutes, depending on the topics to be discussed and questions of parents. Others observed that the frequency and duration declined as the program went on. In addition to the telephone appointments and home visits, parents and therapists were also in touch with each other by e-mail and WhatsApp. In a few cases, the therapist also (indirectly) instructed the primary care physiotherapist or day-carer.

Many therapists remarked that some *home visits* did not take place because of parents being busy, their own planning, travel time, illness, or because it was combined with an appointment in the rehabilitation center. Moreover, therapists and parents often agreed that the third home visit did not have an additional benefit over contact by telephone.

Therapists mentioned that the planning and preparations, such as the task-analysis, as well as the coaching (watching video-recordings, adjusting the treatment plan, telephone appointments, and home visits) were more time-consuming for them than anticipated. The peak load at the beginning of the program required flexibility and investment of their own time.

**Theme 1.2: The Data Sharing System Could Not Be Used as Intended.** Many parents and therapists reported that the data sharing tool Quli did not function as expected. Problems experienced included logging in as well as making, uploading, sending, and watching videos. Many parents found a more satisfying way of sending video recordings, mostly in using WeTransfer or WhatsApp instead. Other parents decided, in consultation with their coaching therapist, not to share video recordings at all. The registration form was mostly sent per e-mail.

The participants who used arQive perceived only occasional problems with logging in, uploading long videos, and viewing videos. However, the registration form could not be transferred via arQive and was sent per e-mail instead.

**Research Question 2: How Did Parents Experience the Home-based Training Program and How Did They Integrate the Program in the Context of Family Life?**

**Theme 2.1: The Goals Need to Be Suitable.** Parents described that, for the goal setting process, it was beneficial when targeted activities were part of daily routine. Those goals were the most convenient ones for families to practice. In particular, for the child practicing these recurring activities, it felt least like doing therapy. Parents also observed that children made most progress when goals were meaningful to the child. On the other hand, parents also experienced that it was beneficial if a goal was a play activity or if a goal allowed for variation of the activity to be practiced. Additionally, it was considered important for defined goals to be realistic and age-appropriate. Lastly, both parents and therapists indicated that it was important that goals be suitable to the specific home situation and season. Activities related to coats or shoes were, for example, difficult to practice consistently in good weather and, conversely, bad weather negatively affected practice of outdoor activities.

Parents appreciated the opportunity to establish new goals during the program. However, some others would have preferred fewer goals to practice, because they found it challenging to divide their attention between five goals in limited training time.

Therapists observed that, when goals were achieved or a ceiling level was reached, parents started searching for how to continue the practice. In this 'generalization phase,' they applied the learned skill in a variety of situations, rather than practicing the activity in the original situation for which the training was initially provided.

**Theme 2.2: The Training Should Be Appealing to the Child.**

Parents stressed that it was beneficial to make training appealing and stimulating to the child. For example, one parent explained:

[...] that it [training] is not an obligation, but that it remains fun. [...] it is important that you train, but I think the most important thing is that the fun in the training, for us as a parent and for the child, must remain the highest priority. Like: 'gosh, that is fun, we are going to do this now' and not: 'oh gosh, we need to again'. (parent)

Strategies that parents used to accomplish this varied with the child. They generally involved not emphasizing activities as being therapy nor imposing practice, but rather practicing when the child showed that it felt like performing the activity, and using a playful, enthusiastic, and varied approach. This required a certain amount of creativity of parents in the provision of training, which they became better at during the program. In addition, parents were challenged in selecting suitable training materials and offering subsequent steps of increasing difficulty. A parent suggested creating a database of exercises, games, and ideas for parents in order to offer variations of certain bimanual activities.

**Theme 2.3: Training of Activities of Daily Living Were Easily Implemented.** Parents implied that they successfully managed to integrate training of activities of daily living in the family routine. Talking about this topic a parent said:

The things that we proposed are of course practical things that our son encounters in daily life, in his daily routine. So if that came along, like pulling up the pants, closing the zipper, eating from a bowl: in fact, you encounter that every day and then you can train that every day. And then it also makes sense for him to train it and [...] that way it just comes back daily and you can just train at times when it is necessary, and that it occurs. And that actually works well. (parent)

Practicing such tasks, therefore, became a habit: tasks were practiced automatically, without having to think about or schedule them. Moreover, the child did not experience these training moments as therapy. As a result, these training activities became routine, being practiced using the same techniques following the program, and often continuing to improve after the program had ended. However, after the program parents no longer created additional practice moments, as they had during the program.

**Theme 2.4: Parents Were Well Able to Provide Training to Their Child.** Parents said that they, as well as their child, were not aware of the parents' role as 'therapist.' As one parent said:

For him, it is actually just playing with his daddy or with his mummy. And that we have a purpose in that, he is not aware of. (parent)

Parents did not experience separate roles, but explained that providing the therapy naturally mixed with their usual parenting role. Additionally, parents liked to remain in the role of parent to their child and did not want to impose training. Sometimes parents struggled because their children were more resistant in their trusted home situation than they were with therapists.

**Theme 2.5: The Involvement of the Extended Family or Social Environment Was Limited.** Parents said that the involvement of grandparents in the training varied. In some families,

grandparents, particularly those who provided structural child care, were actively involved in the training. The degree to which they were instructed by parents and how much time and effort this required also varied. Other parents chose only to practice with their child themselves, to keep control. Parents often informed other persons involved in the child's life, like teachers, about the family's participation in the home-based training program, the goals of the training, and sometimes more detailed instructions, although they had no or a limited role in the training. Parents thought that training activities performed by grandparents or at (pre)school not within their sight was disadvantageous, because others practiced in a way that the parents were not satisfied with.

**Theme 2.6: Completing the Registration Form and Using the Data Sharing System Was Burdensome.** Parents complained that completing the registration form every week was a burden for them for several reasons. Filling in and sending it to the therapist was time-consuming. In addition, it was troublesome having to keep it in mind at all times and to retrospectively quantify the time practiced, especially for goals that were incorporated into the daily routine. Thus, they experienced it as a lot of paperwork. Also, parents had trouble completing the form on their device, or preferred keeping track on paper.

Quli was also described as nonuser-friendly, because parents needed a laptop either to film or upload videos. It would have been more convenient for parents to both film and send the video recordings with their smartphone with the push of a button. The problems encountered cost parents much time and caused a lot of frustration and irritation. In the opinion of participants who used arQive, this was a pleasant system.

**Theme 2.7: The Coaching by the Therapist Was Reinforcing.** Although one parent would have preferred a more critical approach, the positive feedback and confirmation by the therapist that they were doing well generally reinforced parents and children. The following comment illustrates this:

As a parent, you just do something. I mean, I did not obtain a diploma for it. You have an idea about how to handle your child well, but if someone else sees that on a video and then gives you feedback and that is generally positive, yes, it is nice to hear from an outsider that you are doing quite well. That gives you confidence as a parent. (parent)

**Theme 2.8: The Training Was Time-consuming.** Parents stated that they perceived the program to be very time-consuming. They felt that it was an extra focus of attention that was difficult to fit into already busy family life, including work, school, health-care-related tasks, and leisure activities. As one parent put it:

Perhaps it is just a feeling. You have to, there is just an extra point of attention during the week. [...] I experience family life as quite busy and hectic next to a busy working life. So you also have to think: oh yeah, we still have to practice or train with him. We have to fill in the form. We have to make a video-recording. And that is also a repetitive thing. And I think that is quite time-consuming. (parent)

The treatment goals that did not involve daily returning activities required parents to find time to offer training. On school days, there was little time left for training, and children were often tired after school. During holidays and days off, it was harder to comply with the training program as the days were less structured. Some parents chose at times to sacrifice leisure activities for the purpose of training, whereas others did not. Parents also had to choose to what extent they put their and their child's time and energy in either the home-based training of bimanual activities or in other developmental aspects that required attention, such as gross motor activities or cognitive learning skills.

In most families, both parents naturally alternated supervision of training. For parents, this was convenient when they were not in the mood or had lost their patience. The child also benefited from being approached in different ways. Siblings were generally not involved in nor affected by the training. However, for parents it was sometimes challenging to divide their attention between their children because of the needs of the training. Also, it appeared challenging to provide the training while filming at the same time. The home-based training enabled parents to flexibly arrange their schedule themselves, though, and did not require leave from school or traveling to the rehabilitation center. However, distractions in the home situation could be a drawback. One parent explained:

At the moment that you just plan certain things, like: well, we are going to do that and that and that, and the doorbell rings and there is a friend at the door to ask if she comes to play outside, then it is made very difficult for her to say: 'no, I have to do therapy now and I cannot play outside'. Well, then you very easily say: then we do it [practice] another time. (parent)

For some parents, being occupied with the training and seeing progression was more relevant than the practice time, while others were eager to adhere to the prescribed training hours. A therapist wrote:

I had to put the rules of the research in perspective as the parents felt a lot of pressure. If they continue to give so much weight to this, they will not hold on and it will be very burdensome. I spent time on putting these demands into perspective. They should benefit from it and it must be feasible within the situation. (therapist)

Prior to the start, parents underestimated how time-intensive the program would be. They were relieved when the program was finished, as the need to exercise stopped.

#### **Theme 2.9: The Program Duration Was Too Intensive.**

Parents as well as therapists felt that 12 weeks working on the same goals was too long for the parents and the child to continue being motivated. They suggested reducing the duration to eight weeks. They also suggested approaches combining home-based and center-based training. A suggested example of such a hybrid model was that the child would be seen at the center once every three weeks, and the parents would provide training at home for the other two weeks. They also argued that it would be too intensive to perform home-based training continuously during the child's rehabilitation trajectory.

#### **Theme 2.10: The Program Was Demanding for the Child.**

Parents described that part of the time their child liked to perform the training activities and enjoyed the attention of

the parent that went along with it. At other times, the child got frustrated or angry and showed resistant behavior. This occurred mainly if the child felt obliged to practice, if the activity was difficult for the child, and/or if the child was tired or moody. Sometimes parents related this to the child's toddler age.

Some parents felt that the training did not impose stress on their child, while others thought that the training was demanding. This expressed itself in tiredness, in a few cases negatively affecting school results or generating the need of an afternoon nap. For some children, the filming was an extra motivation to show to the therapist what they learned, whereas others did not like to be filmed.

**Theme 2.11: Bimanual Performance Improved.** Parents indicated that their child's performance of the activities targeted by the treatment goals improved substantially. Some children accomplished certain tasks even subconsciously, without focused attention on the performance. The performance of some activities improved more than others. Parents attributed this to the extent to which an activity was trained. The performance of activities that were integrated in daily life improved most. The parents of most children also reported an increase of spontaneous use of the affected hand in bimanual activities that were not related to the goals set, and improved performance of these activities: like one parent put it:

So there are more and more activities that he first said of: 'I cannot, you must do it'. He now wants to do that himself. So he also becomes more independent in that two-handed activity. He just uses the right [hand] very well. And that is just great to see. (parent)

In addition to the parents and therapists, other persons who were involved in the child's life, like teachers, complimented the child's improvements. After the program ended, the progression regarding most treatment goals continued. However, when children did not keep practicing activities or did not integrate these in daily life, parents noted that the performance declined. On the personal level, parents observed that their child was proud if it succeeded in completing a task, that the child's self-confidence grew, that it got more eager to perform activities by itself, and that independence increased. Parents regarded the overall program highly positive, because the results achieved outweighed the effort they put in.

#### **Theme 2.12: The Program Both Positively and Negatively Affected Parents.**

Parents declared that the home-based training program was a stimulus for them to consciously put effort into practicing with their child. It enhanced their awareness that as parents they were able to get good results when practicing at home. Moreover, it made them understand better how to teach their child, as they learned a certain way of thinking with regard to skill acquisition. Sometimes parents also got a better insight into the personality of their child. This made that parents felt more competent and confident at training with their child. The progress of the child motivated and stimulated parents to keep going. The results gave them positive feelings of satisfaction and pride, which meant that they enjoyed

performing the training. Parents also mentioned that they appreciated that the program gave them a more active role, more control, and more responsibility in guiding their child and the rehabilitation process. As one parent said:

I am actually very positive in the sense that I find it very nice that as parents we have literally something to do. Because you, it sometimes feels so helpless that you cannot really help him, and this is really just very concrete. (parent)

One parent felt very responsible for teaching the child but felt that she lacked knowledge in occupational therapy. Moreover, she missed the therapists at the rehabilitation center keeping an eye on the child and its general development. This made that the home-based training feel like a lonely process for her.

For some parents, the home-based training was not stressful at all, while others felt varying degrees of stress. Parents generally felt that the term 'stress' was too strong to describe their feelings: they used words like 'frustration,' 'irritation,' and 'unrest.' The prescribed intensity of the training was the most stress-inducing factor. This included making time for the training and the urge to meet the required training hours. Parents experienced most stress at the beginning of the program, when they were still figuring out how to implement the training.

### **Research Question 3: Which Components of the Home-based Training Program Did Contribute to the Impact of the Program?**

**Theme 3.1: The Manual, Instructional Videos, Task-analysis, Home-based Training, Video Recordings, and Coaching by the Therapist, Including Telephone Appointments and Home Visits, Were Valuable.** Therapists indicated that the program was complex and it took a while for them to get accustomed to it, although this was a prerequisite for coaching parents. The *manual* was clear and useful as a reference.

Parents were positive about the *instructional videos*, although many had little or no recall of their opinion of them during the interviews. One parent stated:

Those instructional films, those work very well, because it really gives a good picture of [...] what you can do yourself in the training. (parent)

Therapists reasoned that the *task-analysis* helped them in defining the training plan and in coaching parents, particularly at the beginning of the trajectory. Normally, they only did an analysis mentally and gave treatment according to what they felt was right to do. The structured task-analysis made them consciously think about how to work toward a goal within a certain number of weeks. They shared and/or discussed the task-analysis with parents. Using the task-analysis, therapists took parents through the process and the therapists' way of thinking: what steps to take in the development of the child's learning of a task? What makes a task easier or more difficult? How to carry out the training? What are points of attention for each goal? Both therapists and parents thought that this information was supportive for parents and enabled them to teach their child other activities themselves.

Parents emphasized that the strength of the program was the training in the home situation (i.e. *home-based training*). They considered it a valuable addition to the center-based therapy programs already available, as the comment below illustrates:

I think particularly by considering how you can practice certain actions in the home situation, just brings so much peace, and without the feeling that you are practicing all of the time. (parent)

The therapists stated that the *video recordings* were valuable for coaching parents. They could retrieve a lot of valuable information from the videos: how parents instructed the child, the interaction between child and parents, how well the training could be applied by parent and child, ambient factors (e.g. the presence of siblings or disruptive radio sounds), the impact of the training, and achievements of the training. This enabled therapists to follow the process and, in subsequent coaching, they could respond to what had happened at home: knowing the conditions involved made it easier for them to think things through. It enabled them to give feedback to parents, and to provide more focused coaching and more specific advice. It also helped them to take parents along in the process, which helped parents to understand how goals were composed and how activities and training were related to the goals. Therapists emphasized the importance of filming in particular those activities that were difficult or that parents had questions about, since there the therapist could really make a difference. If videos were of poor quality or rotated, coaching based on the video recordings was felt to be difficult. Parents were also positive about the video recordings. They benefited from the tips they received from their coaching therapist in response to the videos. For the remedial educationalists, it was enriching to observe behavior of parents and children in the videos. They appreciated being able to view the footage themselves, from a different viewpoint than the therapist. They referred to the video recordings in conversations with parents and the therapist.

Parents stated that they highly appreciated the *coaching by the therapist*. They thought that therapists were enthusiastic, positive, committed, and available when they needed them. Parents received tools, tips, and advices that were very helpful to them. This included suggestions about dividing a task into sub-tasks (e.g. to start practicing closing the zipper, instead of hooking it in), motor performance (e.g. to hold the cutlery differently), organization of activities (e.g. practicing zipper use while the jacket lies on the table in front of the child), materials to be used (e.g. using a large zipper instead of a small one), innovative variation in offering activities (e.g. creating a contest), and dealing with child behavior (e.g. introducing a sticker reward chart). Parents also made purchases on advice of the therapist, for instance a more suitable chair or left-handed scissors.

Therapists thought the *telephone appointments* were important for various reasons: to have regular contact with parents, to check how things are going, to be on the same page with parents, to indicate points of attention after seeing the videos, to evaluate last week's agreements and difficulties parents encountered, and to confirm that parents were on the right track. In a few cases, therapists called both parents alternately,

to enable them both to receive feedback and ask questions. Although this was sometimes difficult to plan, it was beneficial to speak to both parents.

Therapists defined that the first of the *home visits* was very valuable, especially if they did not know the child yet. It was particularly beneficial to see the home and family situation: the house and the environment where the family lived, the conditions for the training (e.g. the child's seating position at the table), and the attributes and toys that were available and that might be used during training. Additional aspects that were discussed during the first home visit included the personal goals, the approach for training of the targeted activities and points of attention, training moments that would fit into the daily routine, care of siblings, and questions of parents. In one case, the therapist observed one of the targeted activities at the playground, as this had not been possible in the rehabilitation center before. Sometimes, the second home visit was also useful to help the therapist to think through and provide suggestions relevant to the specific home situation, for instance to discuss topics in more detail, to adjust the program and give advice on how to approach the training, or because of goals that were changed. The third home visit had little added value for therapists. As with the therapists, parents indicated that the home visits had added value to them in showing performance of activities in person. In one case, the parent explained the effect of modeling by the therapist:

If she writes it down, she puts it exactly the same. But in my case that just works, I remember it better, it does work better if I just see it at such a moment and someone doing it, than that I have it written down on paper. (parent)

For a child whose goals involved largely school-related activities, the parent appreciated one home-visit's taking place at school.

**Theme 3.2: The Number of Telephone Appointments and Home Visits Need to Be Reduced or Customized.** Parents considered the planned frequency and duration of *telephone appointments* too much at the end of the program. A decreasing and customized coaching intensity as the program developed was suggested.

In general, therapists and parents indicated that three *home visits* in the training period was a lot given the pressure on parents as well as therapists visiting families in the evening. Also, the travel time for therapists to visit families was significant. They suggested that the number of home visits could be either reduced or more customized.

**Theme 3.3: The Registration Form Had Limited Added Value.** Some parents felt that the format of the *registration form* was not very useful:

[...] those registration forms add nothing for us, has no added value. It only generates unnecessary irritation. (parent)

These parents did not attach importance to the time practiced, but the form provided others with something to hold on to. The therapists observed similar differences between parents: some actively filled in the form, whereas it was not part of the routine of others. From the therapists' view, this led to parents

writing down just anything, which was not relevant. Therapists did not put much emphasis on the use of this registration form because this would have been counter-productive.

Therapists recognized an added value of the form in that it made parents aware of and motivated to practice. They considered parents applying therapy regularly as more important than the specific training duration. Some parents generalized the training time (i.e. not only time-on-task, but time spent within a broader activity), which prevented parental stress. The registration form provided the therapists with insight into the days and total time practiced, to be used as a subject of discussion with questions like 'why did you not succeed?', 'what can we do differently?' or 'what will help you?.' However, for the therapists, the registration form had lower priority than the video recordings. One therapist did not use the form, as it felt as if she was checking up on parents. The remedial educationalists did not utilize the registration form.

**Theme 3.4: The Added Value of the Coaching by the Remedial Educationalist, Including Telephone Appointment, Varied.**

Concerning the *coaching by the remedial educationalist*, the remedial educationalists explained that, for most children, their role was limited to appointments according to the protocol. In these situations, where the relationship between parents and therapist was good and parents had no problems or questions, a more active role of the remedial educationalist was not needed. Hence, the remedial educationalist and therapist had no contact or only occasional contact during informal meetings at the rehabilitation center: to verify that the program was going well; or to discuss concerns of the therapist regarding emotion regulation, behavior, attention, or motivation of the child, or the parents' capability to provide the training. The health-care professionals agreed that the therapist would inform the remedial educationalist if difficulties arose in the course of the program. Remedial educationalists were confident that therapists knew when to approach them and therefore made the therapist responsible for monitoring the family situation and to identify if their support was needed. In a few cases, the remedial educationalist was more involved because of behavioral difficulties. This involved in-depth discussions of the video recordings between remedial educationalist and therapist, whereafter the therapist communicated the advice of the remedial educationalist to the parents. In another family, the remedial educationalist accompanied the therapist during two home visits, and supported the parents by answering their questions. Because the remedial educationalist looks at the child and family from a different perspective than the therapist, they felt it was beneficial to follow participating families. For the families in which they had no active role, the remedial educationalists felt they could not make a difference. However, the remedial educationalists acknowledged that, should parents experience high stress levels, need guidance, or have questions about their child's behavior, the support of a remedial educationalist could be of great value. The therapists appreciated the remedial educationalists' involvement in more complicated cases. Overall, the remedial educationalists felt they had less impact than therapists who were in contact with parents week in and week out. They felt that they were a superfluous part of the program. In agreement with the

before-mentioned, most parents said that coaching by the remedial educationalist was not necessary for them and they saw no advantage in their individual situation. However, they did not mind that it was part of the training program and they appreciated the possibility of consulting the remedial educationalist. They also thought that fellow parents might have a need for it:

I am glad that it is included, because I can imagine that others may have a great need for that, and I think it is also an essential part of it. But for us it does not apply. (parent)

The remedial educationalists reflected that the *telephone appointment* did not bring the opening to parents they would have liked, since it is distant. A second conversation in person would have been better to recognize the needs of parents and to provide guidance to them. However, they also recognized that opportunities for an appointment in the rehabilitation center are restricted, because the program is executed remotely.

#### **Research Question 4: What Contextual Factors with Regard to Children, Parents, and Health-care Professionals Were Associated with Possible Variation in Implementation and Outcomes between Child-parents-health-care Professionals Triads?**

**Theme 4.1: Child- and Parent-related Factors Can either Promote or Hinder Training.** Willingness to learn, motivation, and perseverance of the child positively attributed to training success while, for other children, issues with behavior, concentration, and motivation were mentioned as restricting factors. The child's interest and frustration varied per goal, sometimes against the parents' expectations, as one of the therapists explained:

We had four goals that were really based on daily activities and one goal [...] that was about dressing and undressing a doll. And mother thought: that is very nice for her, because that is something, a play activity. And that turned out to be something that did totally not work, because she really did not want to go along. She wanted mother to do it. And it was indeed difficult, but she really did not want that, while, for example, putting on the jacket, taking off shoes, spreading a sandwich ... Those were, among others, goals, those went very automatic. (therapist)

Parents found that dedication, willpower, perseverance, and patience as parental personality traits were beneficial to the training. Perfectionism was helpful in achieving the required training time, but was also stress-inducing.

Health-care professionals noticed that the home situation had to be strong and the child had to feel good for the program to be a success. The timing of the program was mentioned as another important factor. Implementation of the program when parents and/or the child were already experiencing strain, for instance because of work or school, was difficult.

**Theme 4.2: Motor Learning Strategies Should Evolve around the Child's and Parents' Needs.** Parents for which the implicit or explicit training approach corresponded with their natural teaching style and their child's natural learning style were doing well. Parents who were used to the opposite teaching style struggled and needed quite some time and coaching to get

accustomed with the new approach. It could also happen that the child was not comfortable with the implicit approach, as a therapist explained:

By doing, mother actually said: 'oh, I find out that he actually has much more need for explicit explanation and instruction'. Because the child then literally said: 'but mama, say what I have to do! So how do I hold that scissors now?' (therapist)

Therapists suggested not differentiating anymore between either implicit or explicit motor learning approaches in home-based programs. Rather, aspects of both motor learning strategies should be used in accordance with the learning style of the child, the nature of the parent, and the phase of therapy in terms of skill acquisition and parent involvement.

#### **Theme 4.3: Therapist Coaching Approaches Varied.**

Therapists used different ways of coaching: for a parent who needed a lot of positive reinforcement, a therapist used solution-oriented coaching by asking questions (e.g. what do you see?). A second coaching approach mainly focussed on practicing being fun for the child, which gives the child energy. A third therapist opted for video recordings of herself where she personally addressed the child and gave a message to the parents. The video messages included instructions, for which the therapist imitated the hand function of the child.

It was beneficial if the therapist and the family already knew each other, since they would already have built rapport and would need less time to reach agreement. Parents thinking along and bringing ideas in was also regarded beneficial, which mostly gradually developed during the program. Sometimes therapists wrote down and e-mailed the advices and agreements for goals following the phone call. This worked particularly well for parents who had trouble recalling information discussed verbally.

#### **Meta-inference**

Table 8 summarizes the qualitative and quantitative findings for each research question. The findings of the different components support each other.

#### **Discussion**

This study aimed to evaluate the processes and factors that influenced implementation and impact of a home-based bimanual training program for children with uCP. We addressed (1) the extent to which the program was implemented as intended, (2) parental experiences and the integration of the program in their family life, (3) contributing program components, and (4) contextual factors.

The program was not fully implemented as intended. Findings related to training intensity, motor learning approach, telephone appointments with and home visits by the therapist, and the data sharing system were most evident. The good adherence to the intended training intensity was consistent with the average compliance (62% to 96.1%) of other home-based training programs in children with CP.<sup>8</sup> Instruction or feedback with regard to motor performance being observed in the explicit protocol twice as often than in

**Table 8.** Meta-inference side-by-side comparison table.

Research question	Quantitative results	Qualitative results
(1) To what extent was the home-based training program implemented as intended?	<ul style="list-style-type: none"> <li>- Instructional course: 100% attendance.</li> <li>- Drop-out rate: 22%.</li> <li>- Training duration: median 12.6 weeks (range 11.0–14.7).</li> <li>- Training intensity: median 165 minutes per week, IQR 67.5 (79% of the intended intensity).</li> <li>- Instruction or feedback with regard to motor performance: 20.9% (SD 3.7) and 42.0% (SD 13.7) of the time in the implicit and explicit protocol, respectively.</li> <li>- Telephone appointments with the therapist every week: 57% of the participants.</li> <li>- All three home visits with the therapist: 43% of participants.</li> <li>- Telephone appointment with the remedial educationalist: 77% of participants.</li> <li>- Completion of the intended registration form: 72% of participants.</li> <li>- Use of the provided data sharing system: 29% of participants.</li> </ul>	<p>Theme 1.1: some protocol deviations occurred with training intensity, motor learning approach, task-specificity, telephone appointments, and home visits</p> <p>Theme 1.2: the data sharing system could not be used as intended</p>
(2) How did parents experience the home-based training program and how did they integrate the program in the context of family life?	<ul style="list-style-type: none"> <li>- Not applicable</li> </ul>	<p>Theme 2.1: the goals need to be suitable</p> <p>Theme 2.2: the training should be appealing to the child</p> <p>Theme 2.3: training of activities of daily living were easily implemented</p> <p>Theme 2.4: parents were well able to provide training to their child</p> <p>Theme 2.5: the involvement of the extended family or social environment was limited</p> <p>Theme 2.6: completing the registration form and using the data sharing system was burdensome</p> <p>Theme 2.7: the coaching by the therapist was reinforcing</p> <p>Theme 2.8: the training was time-consuming</p> <p>Theme 2.9: the program duration was too intensive</p> <p>Theme 2.10: the program was demanding for the child</p> <p>Theme 2.11: bimanual performance improved</p> <p>Theme 2.12: the program both positively and negatively affected parents</p> <p>Theme 3.1: the manual, instructional videos, task-analysis, home-based training, video recordings, and coaching by the therapist, including telephone appointments and home visits, were valuable</p> <p>Theme 3.2: the number of telephone appointments and home visits need to be reduced or customized</p> <p>Theme 3.3: the registration form had limited added value</p> <p>Theme 3.4: the added value of the remedial educationalist, including telephone appointment, varied</p> <p>Theme 4.1: child- and parent-related factors can either promote or hinder training</p> <p>Theme 4.2: motor learning strategies should evolve around the child's and parents' needs</p> <p>Theme 4.3: therapist coaching approaches varied</p>
(3) Which components of the home-based training program did contribute to the impact of the program?	<ul style="list-style-type: none"> <li>- Not applicable</li> </ul>	
(4) What contextual factors with regard to children, parents and health care professionals were associated with possible variation in implementation and outcomes between child-parents-health care professionals triads?	<ul style="list-style-type: none"> <li>- Not applicable</li> </ul>	

the implicit protocol substantiates the difference between the implemented motor learning strategies by the parents in both protocols. In a previous study, 36% of motor-related instruction or feedback was found for an intensive center-based program.<sup>27</sup> The rate for our implicit protocol is considerably lower than this previously reported rate, which supports its fidelity. However, as neither interpretation guidelines nor a priori hypotheses exist, caution must be applied to this finding. The moderate compliance rates of therapists' telephone appointments and home visits can be explained by the qualitative comments of participants that the scheduled frequency of appointments was too high at the end of the program and therefore not adhered to. The nonuse of the provided data sharing system was due to the shortcomings of the system for the specific intervention purposes.

Overall, parents experienced the home-based training as positive and worthwhile. They were well able to provide the therapy and did not report the previously described identity tension between their role as a parent and therapy provider.<sup>28</sup> Parents paid particular attention to making the training appealing to the child. Activities of daily living were most easily practiced, which confirms earlier findings.<sup>29,30</sup> Other facilitators for successful integration of the training in the family life were suitable goals and the coaching by the therapist. The latter is in agreement with a study on a partnership home program, in which support from health-care professionals was found as a need of parents when using a home-based program.<sup>28</sup> In the current study, completing the registration form and using the data sharing system were barriers. Altogether, parents found the program time-consuming. This is consistent with results of others, who identified time as a key barrier to implementing an intensive program.<sup>31–33</sup> Parents perceived both training intensity and program duration as too much. At the same time, dosage is known to be one of the most crucial factors in attaining treatment effects.<sup>2</sup> A hybrid model of treatment, merging home-based and center-based elements, was proposed by parents and therapists. This solution may ensure training intensity and at the same time increase feasibility for families. For the children, the program was demanding but parents observed that the bimanual performance of their child improved. The delivery of home-based training also both positively and negatively affected parents. The findings that parents appreciate acquiring an active role and gain confidence were also reported as benefits by Novak et al.<sup>28</sup>

According to parents and therapists, many components contributed positively to the impact of the program: the manual for health-care professionals, the instructional videos for parents, the task-analysis, the home-based training itself, the video-recordings, and the telephone appointments and the home visits by the therapist. The coaching by the therapist being a highly appreciated component of the program is consistent with previous studies that reported that a therapist as coach provides emotional support, encouragement, and motivation, thus promoting adherence.<sup>34,35</sup> Nevertheless, the frequency of appointments was considered too high as the program progressed, and the added value of the coaching by the remedial educationalist varied. This could be attributed to a selective sample of motivated and capable parents

participating in the study and as such needing less coaching. Other parents likely did not opt for the study or were even not invited by their child's rehabilitation team who may have thought the parents unable to provide such home-based training.<sup>36</sup> If the program is to be implemented in clinical practice and a more diverse group of parents to participate, a more intensive coaching process may be necessary for some. Differentiation has to be made in coaching parents, based on their circumstances (e.g. skills, motivation, and context). Moreover, conversations by telephone had limitations for coaching by remedial educationalists. They would prefer in-person meetings, but this would put additional burden on parents. Video-conversations may be a satisfactory resolution. Lastly, the registration form did not contribute to the success of the program.

Child- and parent-related contextual factors can be either a facilitator or barrier in the implementation and outcomes of the program. An important facilitator would be if the motor learning strategy evolves around the child's and parents' needs. Therapist coaching approaches varied depending on the needs of parents and child. We hypothesize that over time, this individualization would further increase, since performing a coaching role as a health-care professional generates a complex learning process during which they acquire knowledge and skills.<sup>13</sup>

The major strength of this study is its comprehensiveness, which is useful in expanding our understanding of the processes of home-based training programs. The mixed methods approach and triangulation at different levels improved the credibility. The results of this study are also subject to certain limitations. First, the guideline by Saunders et al. was used because of its practical approach and feasibility within the study. Alternative theoretical frameworks, such as the Medical Research Council guidance for evaluation of complex interventions,<sup>36</sup> may have been more sensitive to the complexity characteristics of the intervention. Second, the focus group discussions with the health-care professionals were conducted when the last participant had ended the program. As the study period encompassed several years, therapists and remedial educationalists acknowledged that they had a hard time remembering the details of their coaching in the home-based program. Hence, recall bias may have affected the results. Likewise, during the interviews, parents could not fully recall their opinions on the instructional videos they had watched at the very beginning of the program. Third, the COAD-study encountered recruitment problems and consequently potential selection bias.<sup>37</sup> Therefore, the conclusions of this study may not generalize to the entire population of young children with uCP and their parents. Last, during the intervention, some research activities had to take place. Parents as well as the health-care professionals may not have been able to completely disregard this when describing their experiences. This may have influenced the process evaluation.

The findings of this process evaluation imply that home-based bimanual training forms a demanding but promising therapeutic approach with potential for optimization. In clinical practice, we advocate integrating several core



components in home-based training programs: setting meaningful goals, a priori task-analysis, instructional videos, and coaching by a therapist and remedial educationalist by means of video recordings, telephone appointments, and home visits. For the remedial educationalist's coaching, video-call appointments may be more effective than telephone appointments. The frequency and duration of appointments need to be customized to the family circumstances. Implications of other outcomes of this evaluation should be respected for each individual process. Until the optimal training duration is established, a length between eight and twelve weeks is advised.

A natural progression of this study is to confirm the appropriateness of the proposed modifications, by investigating either an amended version of the current program or a new program using a user-centered design in which the recommendations are incorporated. In particular, the consequences of a reduced duration to eight weeks on the motor performance improvements should be examined. Given the importance of the video-recordings in the coaching process, a well-operating data sharing system is imperative. The arQive system seems promising. However, as this was implemented later on in the study, the credibility of this finding is limited. More studies need to be done to establish whether arQive does indeed suffice, or to assess the feasibility of alternatives. A better understanding of interacting variables in implicit and explicit motor learning is an essential next step in defining their eligibility for particular children, parents, and phases of learning. Ideally, a model will be developed to predict the optimal proportion of implicit and explicit motor learning techniques for each individual family and situation. A cost-benefit analysis for the various program components is also a relevant topic for future research. Lastly, following the suggestion of parents and therapists, further work is recommended to explore and test the optimal design of a hybrid model, integrating home-based and center-based training.

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