

Received: 18 November 2018

Revised: 23 September 2019

Accepted: 26 November 2019

DOI: 10.1111/cch.12722

RESEARCH ARTICLE

WILEY

Caregivers' experiences with the new family-centred paediatric physiotherapy programme COPCA: A qualitative study

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Funding information

Swiss foundation for the child with cerebral palsy (Schweizerische Stiftung für das cerebral gelähmte Kind); Swiss Foundation for the Child With Cerebral Palsy

Abstract

Background: Caregivers' experiences during early intervention of their infant with special needs have consequences for their participation in the intervention. Hence, it is vital to understand caregivers' view. This study explored caregivers' experiences with the family-centred early intervention programme "COPing with and CARing for infants with special needs" (COPCA).

Methods: The data of this qualitative study were collected after 6 months of COPCA intervention in 15 families with an infant with special needs. COPCA was delivered by paediatric physiotherapists in training to become COPCA coaches. Caregivers filled out a study-specific questionnaire with three open-ended questions addressing (a) their overall experience with COPCA, (b) what aspects of COPCA they had experienced as important, and (c) what they had learned during the intervention process. The answers were analysed using a content analyses approach.

Results: Respondents were mothers. Interrater reliability of the content analyses of the three questions was twice excellent ($\kappa = .95$ and $\kappa = .92$) and once good ($\kappa = .77$). The content analysis of the first question resulted in four categories and three sub-categories, for example, evaluation of COPCA as a form of intervention and benefit from COPCA. The content analyses of the second question resulted in eight categories, for example, home-based intervention, support from the therapist, and the attainment of competences. The content analyses of the third question generated seven categories and four subcategories, for example, to support the infant autonomously at home and to recognize the competences of the infant, caregiver confidence, and relationship with the infant.

Conclusions: The participating mothers appreciated the COPCA early intervention programme. They especially valued its home-based setting, the support from the coach, and the experience being able to participate as active partners in the intervention make their own decisions. This means that the mothers valued the family-centred, ecological, and relationship-based elements of early intervention that currently are recommended.

KEYWORDS

caregivers' experiences, early intervention, family centred, paediatric physical therapy, qualitative study

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1 | INTRODUCTION

“COPing with and CARing for infants with special needs” (COPCA) is a novel family-centred early intervention programme (Blauw-Hospers, Dirks, Hulshof, Bos, & Hadders-Algra, 2011; Dirks, Blauw-Hospers, Hulshof, & Hadders-Algra, 2011; Dirks & Hadders-Algra, 2011; Hielkema et al., 2010, 2011). COPCA is based on principles of family-centred care (Dirks et al., 2011; Dirks & Hadders-Algra, 2011; Dunst, Trivette, & Deal, 1999; Rosenbaum, 2004) and the neuronal group selection theory (NGST; Hadders-Algra, 2000a, 2000b, 2010). Goal-oriented coaching (Ives, 2008) is COPCA's main intervention strategy (Akhbari Ziegler, Dirks, & Hadders-Algra, 2019; Dirks et al., 2011; Dirks & Hadders-Algra, 2011). COPCA aims to encourage the family's own capacities to stimulate the infant's motor development during daily care in naturally occurring parenting situations (Dirks et al., 2011). Family-centred practice in COPCA means that the COPCA coach supports the entire family in such a way that family's independence and quality of life are maintained and/or promoted (King et al., 2002). The coach aims at understanding parental needs. This forms the basis for providing the family with information required to make informed decisions. In this way, families develop new skills that may enhance well-being and participation of the whole family, including the child with disability. According to NGST, the infant with atypical motor development needs ample opportunities for self-produced motor behaviour, variation, and trial-and-error experiences to improve his or her motor development (Hadders-Algra, 2000b). Practical implementation of NGST means to challenge the infant at the limit of his or her capabilities to actively explore varying forms of real-life situations that offer the infant opportunities for self-produced motor behaviour and trial-and-error experiences.

COPCA's coaching is grounded in the notion that “people possess the inherent capacity to learn and grow, and have the potential to develop competencies and resources that may be used to improve their situation” (King et al., 2002, p. 61). Coaching in COPCA is goal oriented (Ives, 2008); that is, it is solution focused, performance driven, and nondirective. Being nondirective implies that the coach is a facilitator of ideas and actions. Solution focused means that the focus is on finding solutions in order to achieve specific aims. Being performance driven emphasizes the focus on changing actions to improve performance. COPCA occurs in the family's home environment and includes support of the family by shared observations during daily care. While observing, the coach describes the infant's motor activities (“running commentary”). During shared observation, family members may explore and develop their own strategies to cope in daily life with having an infant with special needs. The communication between family members and coach is open, and relationships are based on equal partnership and confidence. The coach is listening, asks reflective questions, and provides suggestions to challenge the infant. Positive feedback is used to confirm, clarify, and explore any needs to attain a goal. The caregivers are informed that development proceeds by means of trial-and-error and self-produced activity requiring ample time and practice. At the start of each session, the coach discusses the goals

Key messages

- Caregivers highly appreciate home-based intervention, support from the therapist, and the attainment of competences.
- During 6 months of COPCA intervention, mothers learned to support the infant autonomously at home, to observe the infant, and to recognize the competences of the infant.
- Learning processes during 6 months of COPCA intervention enabled the mothers to participate as active partners in the intervention process.

for that session with the caregivers. It should be realized that the approach of coaching is relatively demanding for both families and paediatric physiotherapists (PPTs). The family must be ready to play an active role in the intervention process (Akhbari Ziegler et al., 2019).

The first studies on the effectiveness of COPCA in infants at high risk of developmental disorders supported that elements of the COPCA approach, in particular caregiver coaching and challenging the infant to self-produced motor behaviour, are associated with better functional outcome at 18 months (Blauw-Hospers et al., 2011; Hielkema et al., 2011). We know that families with a child with special needs have individual needs of information, understanding, support, and skill development (King, 2009). However, we do not know caregivers' experiences with COPCA, in particular what aspects of COPCA are important to them and what they learn during the intervention process. Information regarding caregivers' perspectives may inform us whether COPCA is tuned to family needs. As caregivers' experiences and their learning processes have consequences for their participation in the intervention as an active partner, it is important to understand their view.

In Switzerland, the COPCA programme is largely unknown. Recently, 15 Swiss PPTs received education to become a COPCA coach; that is, they followed a COPCA course. The course consisted of formal lectures and of guidance of daily physiotherapy practice over a period of 6 months. A study exploring the learning process of these PPTs showed that they quickly learned to implement COPCA's coaching principles (Akhbari Ziegler, Dirks, Reinders-Messelink, Meichtry, & Hadders-Algra, 2018). The course context offered an opportunity to explore caregivers' experiences during 6 months of COPCA intervention. Therefore, the aims of the present study were (a) to evaluate the caregivers' overall experiences with COPCA during the intervention period, (b) to explore useful and helpful aspects of COPCA for the caregivers, and (c) to get insight in their learning processes. To this end, we used a qualitative approach, applying a questionnaire with open-ended questions.

2 | METHODS

2.1 | Procedure

The data were collected in a qualitative study, during which 15 families from the German part of Switzerland with an infant with special needs received COPCA from one of the 15 PPTs participating in a COPCA course (for details, see Akhbari et al., 2018). The COPCA course was coordinated by the developers of the COPCA programme (Blauw-Hospers et al., 2011; Dirks et al., 2011; Hielkema et al., 2011). It consisted of three contact blocks with two intervals of 3 months: The first block consisted of 2 days and the other two of 1 day. For the participation in this evaluative study, the PPTs and caregivers signed a letter of consent. During the course, the families got one COPCA session a week.

2.2 | Recruitment and participants

The PPTs who had been recruited by the first author informed client families about the course and its associated studies. Each PPT recruited one interested family with a young child with special needs, that is, a child with 0 to 36 months' corrected age, who had been referred to them by the paediatrician, because of delayed motor development and/or neurological dysfunction, and who was not able to stand and walk independently. The participants in this study were the caregivers of the children receiving intervention from one of the PPTs involved in the COPCA course. One caregiver per family participated. The background information of the participants is provided Table 1.

2.3 | Data collection and measure

The data were collected during the last session, that is, after 6 months of intervention. The PPT in charge provided the caregivers of the children with a questionnaire to evaluate their experiences with the COPCA intervention. The questionnaire consisted of three open-ended questions: (a) How did you experience the COPCA intervention during the last 6 months? (b) What aspects of COPCA were particularly useful and helpful for you? (c) What did you learn during the process of being actively involved in COPCA sessions? One of the caregivers filled out the questionnaire and sent it within 2 weeks to the first author.

2.4 | Data analysis

Demographic characteristics of the participants were quantified by descriptive statistics (see Table 1). For the evaluation of the questionnaire, the content analysis approach of Graneheim and Lundman (2004) was used (for an example, see Appendix A). The units of analyses were all answers to the three questions. The first step was to identify meaning units—words, sentences, or paragraphs, extracting

TABLE 1 Demographic characteristics of the participants

	N = 15	% = 100
Gender		
Male, n (%)	0	0
Female, n (%)	15	100
Age		
25 years or less	3	20
25–30 years	3	20
31–35 years	4	27
36–40 years	2	13
Over 40 years	3	20
Country of origin		
Switzerland	3	20
Germany	4	27
Balkan States	3	20
Turkey	2	13
Spain	1	7
Sri Lanka	1	7
Africa	1	7
Parents' highest level of education ^a		
Low: n (%)	3	20
Middle: n (%)	8	53
High: n (%)	4	27
Infant's gender		
Male, n (%)	8	53
Female, n (%)	7	47
Infant's age		
0–6 months	5	33
7–12 months	3	20
13–24 month	4	27
25–36 months	3	20
GMFCS level or severity of disorder of the infant		
GMFCS IV–V	6	40
Mild disorder (no CP)	9	60

Abbreviations: CP, cerebral palsy; GMFCS, Gross Motor Function Classification System.

^aLevels of education: low = primary education/junior vocational training, middle = secondary education/senior vocational training, and high = university education/vocational colleges.

one representative statement for each question. The second step was to create codes, that is, condensed meaning units that preserved the manifest content of the statement. The third step was to create exhaustive and mutually exclusive categories and subcategories. A category is an umbrella term for a group of codes that share commonality. It can be seen as an expression of the manifest content of the text and may include subcategories. To cope with the requirements of trustworthiness in these content analyses, (a) the meaning units were extracted from the units of analyses by the first and second authors

independently. Disagreements were discussed until consensus was reached; (b) "draft-codes" and "draft-categories" developed by the first author were critically discussed with the third author and adapted accordingly to create the final codes and categories; and (c) the first and second authors independently assigned all meaning units to a category (and sub-category), and disagreements were discussed until consensus was reached. Interrater reliability between the first and second authors was calculated with Cohen's kappa coefficient (κ ; using Microsoft® Excel® version 12.3.6). The results of the content analyses were reported by descriptive statistics (see Tables 2 and 3).

TABLE 3 Codes and categories summarizing useful and helpful aspects of COPCA

Category	Code
Home-based intervention	Adapted to the conditions at home/own environment
	Intervention at home
	Home equipment applicable
Integration in daily activities/care	Part of daily routine
	Adapted to daily requirements
Benefit for the infant	Developmental progress child
	Child more relaxed
	Changes child
	Better results
	Feeling of success of the child
	Properly varied and challenging for the child
	Challenging for the child
	More support/strengthening child
	Hints to support the infant
	Good realisable hints
Support from the therapist (coach)	Received good support
	Received confirmation
	Supporting my infant by myself
To attain competences	Setting goals by myself
	To do by myself
	Learned to understand my infant
	Learned to play with my infant
	Better recognition of impairments and strengths of my child
Communication	Talking about worries
	Getting answer to questions
	To talk with my partner
Attitude of therapist (coach)	Impression of therapist's (coach's) competences
	Patient and sympathetic therapist
Goal setting	Set every week reachable goals

Abbreviation: COPCA, COPing with and CARing for infants with special needs.

TABLE 2 Codes and categories summarizing experiences with COPCA during the last 6 months

Category	Subcategory	Code
Evaluation of COPCA as a form of intervention		Very good
		Varied
		Suitable for the whole family
		Helpful
		Instructive
		Pleasant
		Satisfying
		Playful
		More like daily routine than therapy
	Benefit from COPCA	Benefit for everyday life
Child learned a lot		
Benefit for the child		Child made developmental progresses
		Adapted to the conditions of the child
Benefit for the caregivers		Mother learned a lot
		Useful hints for new activity
Empowerment		New ideas to support the child's development
		Comforting
		Obtained more competences
		Confirmation
Home-based therapy		Feel better
		Support for the child and the family at home
		An enormous bonus

Abbreviation: COPCA, COPing with and CARing for infants with special needs.

3 | RESULTS

3.1 | Characteristics of the participants

Families were free to choose which caregiver would respond to the questionnaire. All questionnaires were filled out by mothers. The age of the mothers ranged from 20 to 43 years (mean age 32 years, standard deviation 7 years). The mothers came originally from seven different countries and had different levels of education. Eight mothers had an infant below the age of 1 year old. Six mothers had an infant with a severe disorder. For details, see Table 1.

3.2 | Interrater reliability

Interrater reliability of the allocation of the meaning units extracted from the first and second questions was excellent ($\kappa = .95$ and $\kappa = .92$,

respectively); it was good ($\kappa = .77$) for the meaning units extracted from the third question.

3.3 | Caregivers experience with 6 months of COPCA intervention

The content analyses of the question about the overall experiences with COPCA resulted in four categories and three subcategories (Table 2; in the text indicated by quotation marks). All mothers qualified the COPCA programme resulting in the category "evaluation of COPCA as a form of intervention." They described COPCA as a varied, helpful, and satisfying intervention. A 37-year-old mother with a 5-month-old girl with a mild disorder stated: "The coach explored together with us the best possible ways for our child to develop." Thirteen mothers mentioned the "benefit from COPCA." Three mothers primarily noted a "benefit for everyday life." A 28-year-old mother of a girl aged 2 years 6 months who is functioning at Gross Motor Function Classification System (GMFCS) level IV said: "COPCA became a part of our life, that we can apply always in everyday life." Three other mothers experienced particularly a "benefit for the child." A 23-year-old mother of an 8-month-old boy with a severe disorder remarked: "The coach observed how he is and adapted the programme accordingly." In the subcategory "benefit for the caregivers," new possibilities to play and useful hints were mentioned by seven mothers. A 41-year-old mother of a 9-month-old boy with a mild disorder answered: "I am less hectic, this has a positive effect on the whole family." Three mothers made statements to the category "empowerment." A 38-year-old mother of a 3.5-month-old boy with a mild disorder mentioned: "We were reinforced that we are on the right way." Three mothers brought up the category "home-based therapy." The 23-year-old mother said: "Home-based therapy is an enormous bonus for our child, he feels safe in this familiar environment." No mother expressed unhelpful or negative experiences.

The content analyses of the question about useful and helpful aspects of COPCA resulted in eight categories (Table 3). "Home-based intervention" was of major value for most of mothers; it was explicitly mentioned by 11. They appreciated that therapy was adapted to the home conditions. A 31-year-old mother with a boy aged 1 year 7 months who is functioning at GMFCS level IV said: "Also that that practice was adapted to the conditions at home and I didn't have to make a transfer from the outpatient clinic to the environment at home." Another aspect referred often was "integration in daily activities/care." Some mothers (five out of 15) experienced the intervention as part of daily routine and adapted to daily requirements. The same mother reported: "It felt less like therapy but much more like everyday life." Eight mothers mentioned a "benefit for the infant." They reported about changes in the acquired abilities of their children, that they spend more time in supporting the children, and that the children had been challenged. The 23-year-old mother with an 8-month-old boy who is functioning at GMFCS level V remarked: "Consistently challenging

situations that generate feelings of success were offered to the infant." A further helpful aspect for nine mothers was the "support from the coach." Mothers received confirmation and helpful hints in a way that they felt well supported. A 42-year-old mother with a 1-year-old boy with delayed motor development and asymmetry stated: "Especially the confirmation that we do everything right." The 23-year-old mother answered: "Valuable assisting ideas, easy to implement." "To attain competences" was also an aspect for seven mothers. They acquired different competences like supporting the infants, setting goals, or learning to play with the infant. A 32-year-old mother with a 1-year-old girl with delayed motor development remarked: "I can work on and arrange themes I regard as essential." Four mothers mentioned the aspect "communication." Talking about worries and getting an answer to questions was helpful for them. Also, the "attitude of the therapist (coach)" was an aspect we identified ($n = 2$). Mothers reported that the therapist gave the impression of being competent, patient, and sympathetic. For a 37-year-old mother with a 5-month-old girl with Curschmann-Steinert syndrome, "goal setting" was a helpful aspect: "It was good for us to set every week goals which our girl could meet."

The content analyses of the question about the learning processes of the caregivers resulted in seven categories and four subcategories (Table 4). The category "to support the infant autonomously at home" means that the mothers had learned to support development of the infant in daily life not only in the presence of the coach but also autonomously between the intervention sessions. All mothers mentioned this aspect. In this category, two subcategories could be distinguished. First, the mothers gained "knowledge about possibilities to promote child development"; that is they learned to offer the infant appropriate exploration situations, to give the right quantity of help, to appreciate that play is an excellent means to practice, how to implement this knowledge in a playful way, and to give the infant more time ($n = 13$). A 38-year-old mother with a 4-month-old boy with muscular hypotonia answered: "I can demand something from him, adjusted to his capacity." Second, two mothers mentioned that they developed strategies "to create an enriched and supportive environment at home"; that is, they learned how to create an enriched, development-supporting environment. A 28-year-old mother with a girl aged 2 years 6 months who is functioning at GMFCS level IV stated: "I installed a motor activity area in our house." Another learning category we distinguished was patiently and accurately "observation of the infant" before acting or reacting ($n = 4$). Furthermore, two mothers "recognized the competences of the infant"; that is, they now realized that the child needed less help and was competent to perform many activities independently. Five mothers reported "to understand infant development" better. They became aware that development needs time and is not following a fixed programme. A 23-year-old mother with an 8-month-old boy with muscular hypotonia and epilepsy stated: "I understand now, that the development of my infant is not like as described in books, e. g., crawling with seven months." Another learning effect was that

TABLE 4 Codes and categories and subcategories summarizing learning processes of the caregivers

Category	Subcategory	Code	
To support the infant autonomously at home	Knowledge about possibilities to promote child development	To challenge the infant adequately	
		To challenge the infant playfully	
		To support development	
		To offer appropriate exploration situations	
		Right quantity of help	
		To support the infant	
		To practice with the child	
		To know possibilities for developmental stimulation at home	
		To practice motor activities playfully	
		How to play with the child	
		I have to do less	
		Not to react immediately	
		Let the child do more by herself	
	To give the infant more time		
	To create an enriched and supportive environment at home	To create an enriched environment at home	
		To create an enriched development-supporting environment	
		To observe the infant	To observe the infant precisely
			To observe the infant
			To first observe the infant
To recognize the competences of the infant		To observe the infant how he practices with a lot of pleasure	
	Child has competences		
To understand infant development	Child can do more by herself		
	To recognize small developmental steps		
	Development not according to a programme		
	Development needs time		
	How the child progresses		
Caregiver confidence	The infant determines the tempo		
	Certainty in handling my infant		
	Handling the situation better		
	Certainty		
	To stay quiet		
Relationship with the infant	Confidence in and understanding of the infant	How to feed my infant	
		Confidence in the infant	
	To be responsive towards the infant	Understand the infant better	
		To listen to the child	
		Pay attention to the needs of the child	
		Promote infant in situations he feels comfortable	
		Caregiver attitude	Knowledge about the influence of own attitude
			To look beyond one's own nose
Enforce nothing			

some mothers ($n = 4$) gained “confidence” in handling the situation of having a child with special needs. A 41-year-old mother with a 9-month-old boy with muscular hypotonia reported: “Certainty in handling my infant in continuous development, also when sometimes only little steps are recognizable and perceptible.” Five mothers commented that they learned about the “relationship with the infant.” We divided this category in two subcategories, (a) “confidence in and understanding of the infant” and (b) “to be responsive towards the infant.” Relating to the second subcategory, the 23-year-old mother with an 8-month-old boy who is functioning at GMFCS level V commented: “I paid attention to the needs of the child.” Three mothers made statements concerning their own attitude. The 31-year-old mother with a boy aged 1 year 7 months who is functioning at GMFCS level IV became aware about the influence of her “attitude.” She learned: “To reflect, how my attitude has an influence on how intensive I practice with my child, e. g., do I consider it beforehand too fatiguing to do a certain exercise ... or do I expect things from him.”

4 | DISCUSSION

The present study explored the perceptions of caregivers of young children with special needs with 6 months of COPCA intervention. The data indicated that caregivers perceived the COPCA programme as a positive and beneficial experience. They valued in particular the programme's home setting and the supportive role of the coach enabling caregivers to support the child in daily life.

4.1 | Experience with 6 months of COPCA intervention

All mothers described their experience with COPCA as positive and beneficial. It is conceivable that this favourable evaluation was especially brought about by the home setting of the COPCA intervention, as the review of Kruijzen-Terpstra et al. (2014) underlined that parents of children with cerebral palsy favoured home intervention. Parents preferred the home setting rather than the clinical setting as the site of intervention, as they found it challenging to implement instructions received at the clinic in the home environment (Kruijzen-Terpstra et al., 2014). Fortunately, early intervention programmes are often delivered at home. Yet this holds true mainly for programmes that aim at general developmental stimulation, not for early physiotherapeutic intervention, as may be illustrated by the studies included in Spittle's systematic review on the effect of early intervention (Spittle, Orton, Anderson, Boyd, & Doyle, 2015). Thirteen studies included in the review dealt with programmes delivered in the home setting; only two evaluated a physiotherapeutic or occupational therapy programme; the others assessed the effects of a general developmental stimulation programme. Of the remaining 12 studies, seven evaluated physiotherapeutic interventions and the other five general developmental programmes. This suggests that the caregivers'

satisfaction with PPT services and its associated active participation of the caregivers may increase if the service is delivered in the home setting.

The majority of mothers mentioned that they had appreciated the support of the PPT. Family support is considered a critical factor determining whether or not families engage as active partner in intervention (Hinojosa, 1990). In the current intervention, the PPT acted as a coach, which enabled the caregivers to make their own decisions and to discuss in a respectful way the goals for the near future. This in turn resulted, as the mothers mentioned, in knowledge about the short-term, achievable goals that could be integrated realistically in daily caregiving activities. These spontaneous remarks of the mothers fully correspond to parental experiences summarized in the review of Kruijzen-Terpstra et al. (2014). They are also in line with the report that COPCA intervention promotes family empowerment (Hielkema et al., 2019).

The mothers reported that they had acquired new skills, knowledge, and behaviours on how they autonomously could promote the child's development. They had learned how to stimulate the infant's motor development during daily care, for example, how to challenge the child's performances and to offer the infant opportunities for trial-and-error experiences. Two recent systematic reviews concluded that these components are the most promising ones of early physiotherapeutic intervention (Hadders-Algra, Boxum, Hielkema, & Hamer, 2017; Morgan et al., 2016). The integration of these intervention components in daily life may result in a higher dosing of “practice” and therewith increase the chance of a beneficial effect (Hadders-Algra et al., 2017).

4.2 | Methodological considerations

This is the first study exploring caregivers' experiences with COPCA. To cope with the requirements of trustworthiness in qualitative research, a multistep procedure was performed to endorse reliability. The study also has limitations. First, no fathers participated in the study, limiting our knowledge to mothers only. This may have affected the results, as King et al. (2008) identified differences in paternal and maternal evaluations of care. Second, we did not include questions addressing explicitly unhelpful or disagreeable aspects of COPCA. This may have resulted in positive bias. Nevertheless, none of the mothers mentioned negative experiences in response to the first question. Third, the PPTs were in the process of becoming a COPCA coach, which may imply that they did not provide full-blown COPCA intervention. However, our additional study (Akhbari Ziegler et al., 2018) indicated that the most important component of COPCA, that is, COPCA's coaching principles, are learned quickly by PPTs.

4.3 | Concluding remarks

The participating mothers appreciated the COPCA early intervention programme. They especially valued its home-based setting, the

support from the coach, and the experience that COPCA enabled them to participate as active partners in the intervention process and make their own decisions. This means that the mothers valued the family-centred, ecological, and relationship-based elements of early intervention that currently are recommended.

For future research on caregivers' experiences, we recommend that also fathers participate, as this would allow for the unravelling of differences between maternal and paternal views on paediatric physiotherapy in young children. For a more comprehensive insight into caregivers' experiences, we recommend to explicitly address potentially negative experiences with early intervention.

ACKNOWLEDGEMENTS

The authors would like to thank all parents who participated in the study. We also acknowledge the feedback from Tineke Dirks, PT, and Heleen Reinders-Messelink, PhD, on an earlier draft of the manuscript and the advices of statistician André Meichtry. The study was financially supported by Swiss Foundation for the Child With Cerebral Palsy (Schweizerische Stiftung für das cerebral gelähmte Kind).

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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How to cite this article: Akhbari Ziegler S, Mitteregger E, Hadders-Algra M. Caregivers' experiences with the new family-centred paediatric physiotherapy programme COPCA: A qualitative study. *Child Care Health Dev.* 2019;1–9. <https://doi.org/10.1111/cch.12722>

APPENDIX A: | EXAMPLES OF CONTENT ANALYSIS ACCORDING TO GRANEHEIM AND LUNDMAN (2004)

Meaning units	Codes	Categories
Especially the confirmation that we do everything right.	Received confirmation	Support from the therapist (coach)
To talk about my worries related to the development of my child.	Talking about worries	Communication
Especially helpful is to move in the own environment and therefore not to be forced to rethink something you learn or noticed in the outpatient clinic into the own everyday life and environment.	Adapted to the conditions at home/own environment	Home-based intervention