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RESEARCH PAPER

Parents' experience of undertaking an intensive cognitive orientation to daily occupational performance (CO-OP) group for children with cerebral palsy

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ABSTRACT

Purpose: The purpose of this study was to explore the experience of parents of children with cerebral palsy (CP) who participated in an intensive cognitive orientation to daily occupational performance (CO-OP) group program addressing child chosen goals.

Method: Participants were six parents of children with CP who participated in a CO-OP upper limb task-specific training program. Parents participated in semi-structured interviews conducted via phone. A grounded theory approach was used. Interviews were transcribed verbatim and coded to identify categories and overarching themes of the parent experience of CO-OP.

Results: The theory of CO-OP for children with CP was one of offering a unique and motivating learning experience for both the child and the parent, differing from other therapeutic approaches that families had previously been involved in. Five categories were identified: the unique benefits of CO-OP; the importance of intensity; the child's motivation; challenging the parent role; and the benefits and challenges of therapy within a group context.

Conclusion: Parents felt that CO-OP was a worthwhile intervention that leads to achievement of goals involving upper limb function and had the capacity to be transferred to future goals. Intensity of therapy and a child's motivation were identified as important factors in improvements. Further studies using quantitative research methods are warranted to investigate the benefits of CO-OP for children with neurological conditions.

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Motor training; task-specific training; upper limb

► IMPLICATIONS FOR REHABILITATION

- The cognitive orientation to daily occupational performance (CO-OP) is a promising upper limb cognitive motor training intervention for children with cerebral palsy.
- In a small sample, parents perceived that CO-OP leads to achievement of upper limb goals.
- Intensity of therapy, the child's motivation and the parents' ability to "step-back" were identified as important to the success of CO-OP.

Introduction

Upper limb task-specific training interventions are strongly supported in the pediatric neurological population,[1–5] however, little has been published regarding the parents' experience of their child undertaking such treatment.[6,7] It is widely recognized that parents and families play a crucial role in a child's life and participation in rehabilitation programs.[8] The cognitive orientation to daily occupational performance (CO-OP) is a client-centered, goal-focused, task-specific training approach that combines motor learning with cognitive problem-solving strategies.[9] Although there is little published evidence regarding the use of CO-OP for children with cerebral palsy (CP), this approach appears promising.[10–12] This paper explores the experience of parents of children with CP who participated in a CO-OP group, aimed at improving goals related to upper limb function.

Parents and families play a crucial role in the life of a child with a neurological condition.[6,8] Children are reliant on the

involvement of their families in order to access services, and receive an adequate dose of therapy. Given the critical role that parents play, it is important to consider the parent's lived experience of undertaking therapeutic treatments with their child. A number of studies have explored the experience of parents of children with CP undertaking different therapeutic interventions,[6,7] however, none have explored the experience of CO-OP with this population.

CO-OP is an approach used to facilitate achievement of motor-based goals.[9,13] CO-OP combines motor training and learning theories, and differs from other task-specific training interventions in that it is focused first on teaching the child the global problem-solving strategy of goal-plan-do-check.[9] The child then applies this cognitive strategy to their chosen goals to come up with a "plan" to achieve their goal, followed by continued practice of the successful plan to consolidate the learnt skill. The therapist or parent supports this learning through a process of guided discovery and utilizing domain specific strategies.[9] There is high level

evidence to support the use of CO-OP for children with developmental coordination disorder,[14,15] and preliminary evidence suggests CO-OP may be beneficial in other populations such as Asperger's syndrome,[16,17] pervasive developmental disorder [18] and brain injury.[10] A number of authors support the potential benefits of CO-OP for children with CP [12,19] and unpublished studies regarding CO-OP for children with CP have been carried out,[11,20] and are currently being undertaken.[21]

CO-OP for children with CP

Although there is currently limited evidence regarding the use of the CO-OP approach for children with CP, there are a number of factors that suggest this may be a beneficial intervention in this population. CO-OP was designed to assist children with motor planning difficulties who were experiencing challenges learning new motor-based tasks, and motor planning difficulties are very common in children with CP. Although children with CP may utilize differing strategies than other diagnostic groups to achieve their goals, the core components of CO-OP still appear applicable in the CP population. CO-OP is also not limited to use with certain typographies of CP, and can be used with children with unilateral or bilateral and spastic, dystonic or ataxic impairment. Many other upper limb interventions cannot be utilized with such a broad range of children with CP. CO-OP is consistent with client-centered practice in focusing on the importance of children setting their own goals, and empowering children to come up with strategies themselves that assist with these goals. Furthermore, CO-OP is focused on function, rather than impairment, in line with best practice models in current upper limb therapy interventions [22].

As CO-OP is a new approach for children with CP, and the approach is unique from other task-specific training approaches, particularly in regard to the cognitive/problem-solving component, it was felt that it would be important to explore not just the quantitative outcomes (as is being explored in the larger trial [21]), but also to understand the experience of CO-OP for the families undertaking this intervention.

The aim of this paper is to describe the experience of parents of children with CP who participated in an intensive CO-OP group program.

Description of CO-OP group

The CO-OP group was run daily, for approximately 1 h each day, over 10 consecutive weekdays. Parents were expected to be present at every session, and actively participate in sessions, by guiding their children in the CO-OP process during practice of individual goals. In the first session of this group, parents were educated regarding the theoretical background of CO-OP and shown examples of the practical application of CO-OP strategies. Modeling and coaching were provided by an occupational

therapist trained in CO-OP. Study procedures for the CO-OP group have been described in detail in the study protocol.[21]

Methods

Participants

A purposeful sample of parents was used. All parents of children with CP who participated in the CO-OP group during the second cohort of participants for the larger trial [21] were invited to be interviewed. Five of the seven parents approached completed an interview (of the two parents that did not complete the interview: one child dropped out of the study after two sessions due to psychosocial factors, and one parent only attended the CO-OP group for one session). Following data analysis, one additional parent from the fourth cohort of participants was then interviewed to confirm categories and sub-categories identified. Participant characteristics are shown in Table 1.

Data collection

A grounded theory approach [23] was taken in this study, which utilized semi-structured interviews to explore the experience of parents of children participating in CO-OP. An interview guide was developed as shown in Table 2.

Although an interview guide was used, parents were encouraged to expand on any additional themes that were identified during the interview, as per the methodology convention. Researcher memos, as recommended by Stanley & Cheek [24] were used, and any additional categories identified were then explored in future interviews. This system was used to increase rigor, rather than member checking, as per literature recommendation for this grounded theory study.[25]

Procedure

Ethical approval was granted. Written consent was obtained from all parents prior to participation in the study. Interviews were conducted within two weeks of the parents and children completing the CO-OP group program. Individual, semi-structured interviews were conducted over the phone in English. Interviews were audio-taped and transcribed verbatim. Names were removed from transcripts to ensure anonymity. Interviews ranged from 16 to 40 minutes, with a mean of 28.2 minutes per interview.

Data analysis

Data analysis began during the data collection phase, with researcher memos being taken during each interview and emerging categories noted and explored in future interviews. When interviews were completed, two researchers independently reviewed all transcripts. Manual open-coding was then used, with the two researchers jointly reviewing transcripts word for word, line for line, utilizing both constant and theoretical comparisons

Table 1. Participant characteristics.

Parent gender	Child gender	Age (years, months)	Diagnosis	MACS	GMFCS
Mother 1	Male	11, 1	CP; unilateral; spastic	II	I
Mother 2 (twins)	Male	12, 8	CP; bilateral; spastic	III	III
	Female	12, 8	CP; bilateral; spastic/dyskinetic	IV	IV
Mother 3	Male	5, 11	CP; bilateral; spastic	III	II
Mother 4	Male	11, 1	CP; bilateral; spastic/dyskinetic	III	III
Mother 5	Female	10, 3	CP; bilateral; ataxic	I	I
Mother 6	Female	9, 7	CP; unilateral; spastic	II	II

Table 2. Interview guide.

How was your experience of undertaking CO-OP?
How did CO-OP compare to other therapies your child has undertaken?
Has your child continued to use the goal-plan-do-check strategy?
How did your child cope with coming to therapy every day?
Did you like that it was run as a group or would you have preferred individual sessions?
What advice would you give for future CO-OP groups?
Would you recommend CO-OP to other families?

when coding ideas that were then categorized by grouping common ideas; in this way, the meaning of individual words as well as phrases and sentences were of equal importance, in line with recommendations of Corbin & Strauss.[23] Memoing was used during an active process of noting codes and mind mapping individual codes into categories as potential categories and sub-categories emerged. Where researchers did not agree on the categorization of an idea, transcripts were re-reviewed to establish context and discussed until a consensus was reached, with researcher memos being taken each time such a discussion was required. Axial coding was then used to develop connections between sub-categories and a total of five categories, including 13 sub-categories were identified, within one overarching theory. Once the categories were established, transcripts were reviewed to ensure categories were reflective of the overall interviews. “In vivo” coding was utilized and direct quotes were used throughout the analysis process to increase rigor and ensure categories were directly reflective of the participants’ experience. Reviewers agreed that saturation of categories was reached from the five interviews initially completed, and a sixth interview was then conducted to validate the identified categories and theory.

Results

The theory of CO-OP for children with CP was one of offering a unique and motivating learning experience for both the child and the parent, differing from other therapeutic approaches that families had previously been involved in. The core category was one of beneficial outcomes and involvement in CO-OP being “worth it”, despite the challenges. Relationships between categories involving the parent, the child and the context supported this overarching theory.

The CO-OP experience

Improvements and enjoyment

All parents perceived their children showed improvements in goals as a result of participation in CO-OP. Parents used words such as “amazing”, “beneficial”, “grateful”, “valuable” and “priceless” to describe involvement in the CO-OP program.

“It is probably one of the best things we’ve done” Mother 4

“Just to see the pure excitement in X just seeing her handwriting improve in that short space of time. Seeing the joy of her trying to work out what the problems are and to try and find a solution”. Mother 5

“Having a sense of accomplishment over that very short period of time,. Tying his shoe laces is just such a big thing for him, and he just takes it in his stride now. I didn’t think there was anything that was going to work, I just didn’t think he was going to be able to do it” Mother 1

Parents felt CO-OP led to rapid gains for their children. All parents felt that their children enjoyed being a part of the CO-OP group, and stated they would recommend CO-OP to other families of children with CP.

Global problem-solving strategy

Parents perceived that the cognitive component of CO-OP was a “fantastic concept” and appreciated the “freshness” of this approach compared to other therapies. Parents felt that children had come away from the group with a fantastic new skill – the ability to independently problem-solve challenging motor-based activities.

“I don’t think her hands will ever get stronger with all the therapy in the world. But to see her actually have to stop, and think, and make a plan, and then go back to check and see if that plan is working, it’s one of the best gifts that she’s been given” Mother 5

Transference – we want to keep using the CO-OP strategies

Parents were excited by the possibility that their children had learned a “transferable life skill”, that not only helped with their current goals, but they would also be able to apply to future skills. Many parents reported that their children had already begun to apply the global problem-solving strategy of goal-plan-do-check to other tasks.

“Now he’s thinking, well what’s my next couple of goals? He’s looking at setting his own goals, thinking about that himself and what he wants” Mother 4

“I think in the future too it will help him. We plan to continue using that strategy in different areas” Mother 2

Parents also recognized the importance of continuing to utilize the strategies learnt during CO-OP, through the continued practice of skills and applying the goal-plan-do-check strategy to future goals.

Intensity

All parents felt that the intensity (daily for 10 consecutive weekdays) was a key element in the success of the CO-OP program. Parents also recognized that participating in the group during the school holiday period allowed greater opportunity to focus on and dedicate time to their child’s goals.

“I think the everyday focus was really good. It sort of forced you to do it, there was no putting it off, ‘we don’t have to go for another week, so we’re too tired today so lets not worry’. So it kept us on track” Mother 4

“If you’ve got some specific goals . . . just having that dedicated time with your child to try and overcome them, I think really can be life changing” Mother 1

Parents also felt that the intensity of the group enabled consolidation of skills.

“I know with X if she did it once a week, by the time you got in there again, she’d lose it again. So I think the every day was enough to plant it in her head. And that’s the key . . . I think the consistency of it was what made it work”. Mother 5

Although parents felt the intensity leads to good results, they also recognized that it was very hard work, and a huge commitment to attend the daily therapy, but ultimately “worth giving up [their] holidays for”. Parents described the intensity as being “hard work”, “tiring” and “fatiguing” for the family, and recognized that it would not be realistic for all families to be able to commit to such intensity, due to competing demands such as work and family commitments.

Motivation

The child’s personality makes a difference

Parents recognized that motivation was an important prerequisite for success in CO-OP, and that it was easier to use CO-OP with

children who were motivated. Parents also reported observing that children with poor attention and behavior did not respond as well to CO-OP as children who were motivated and able to maintain attention throughout each session.

"I think at the end of the day, it was more about X's attitude and he was reluctant to do a whole lot of things so that was making it a bit harder" Mother 3

The mother of a five year old participant felt that he may have been "too young" to be involved. Another parent felt that a six year old child in their group struggled with the CO-OP concept more than her nine year old daughter, although noted this may have been due to personality as much as age. One mother commented that she was surprised that her 11 year old daughter, who had a mild cognitive impairment, was able to grasp the concept of goal-plan-do-check so quickly.

Handing control over to the child

Parents felt that handing control of therapy over to their child, through the CO-OP process, was empowering and motivating for children who were used to "being told" what to do.

"He's always been instructed what to do . . . it was nice not having a therapist telling him exactly what he needed to do to problem-solve . . . This has made him more assertive" Mother 4

Many parents observed that for the first time, their child self-initiated practice of their goals. Parents felt this change in behavior was directly related to the child being in control, or "putting the ball back in their court". This led to increased practice, which in turn led to automation of skills. Parents also reported that children felt a sense of achievement when their plans succeeded, particularly because children felt their success was their own doing.

Setting specific and "just a few" goals

Parents reported that setting very specific and achievable goals was motivating for children, and facilitated a sense of achievement in a short timeframe. Children leading the goal setting process, and having a combination of practical and fun goals were also identified as important to motivation.

"Setting very specific goals, and not too many, just a couple, and really focusing on just those 3 things was really beneficial, rather than 'we want to do everything under the sun'. Picking things that were a combination of something a bit fun and then picking other things that were essential to everyday life" Mother 4

Focus on function - things that are real to the kids

Parents reported they felt CO-OP was different to other therapies in that it focused on function, rather than trying to "fix" their child's hands. Parents felt this focus on functional use was beneficial for children, and following participation in CO-OP, their child was now thinking about "why" rather than "can't". Parents felt that CO-OP positively shifted their child to focus on possibilities.

"This wasn't about what she couldn't do, it's what she can possibly do". Mother 5

Challenging parent roles and beliefs

Stepping back

An overwhelming theme consistently identified by parents was the importance of "stepping back", and that CO-OP was innately

different to other therapies as it encourages children to rely less on their parents.

"That was probably the most challenging part, us actually learning to step back, which is challenging and some parents may find that quite hard" Mother 3

Parents felt this was a major difference of CO-OP compared to other therapies they had participated in the past.

"I like it made me just take that step back and think about things a little differently, and we've never seen that sort of therapy in practice" Mother 5

Parents recognized that children relished in being given the opportunity to take a lead in their therapy.

"Not giving him the answers was good, I stand back a bit more than I probably normally would. I think he felt that he had made all those achievements on his own, which I think is a good thing". Mother 4

Evolving the parenting role from "doing" to "guiding"

Parents discussed a compelled need to help when parenting a child with a disability, and that CO-OP challenged and reconceptualized the nature of the role of helper. Initially parents found this change challenging but this shifted to enlightening.

"We've been trained as parents to basically step in and do everything for our kids" Mother 5

One parent suggested it was so against her nature to help in a CO-OP way that she might not have joined the study if she had fully understood it before trying it, however, after participation in CO-OP, felt that it was "extremely relevant".

Parents found the expectation that they would be actively involved in facilitating the CO-OP process initially confronting, challenging and at times frustrating.

"I'm not an expert, I'm just a mum" Mother 5

Conversely, parents also felt they themselves benefitted from being actively involved in the CO-OP process. Parents felt they learnt different ways of posing questions, and would be able to model therapist behaviors and apply these to their child's future goals as a result of being present during the CO-OP group.

"Because of the difference in what [the therapist] was teaching, I did need to be part of it, I did need to learn". Mother 6

"So, it's helped me, more than anyone, really. It's helped me to take that step back and allow him to start thinking through things, or allow me to break things down a little more in a subtle way for him" Mother 3

"It is difficult as a parent not to try and solve things for them. Just being able to kind of see you modeling the behavior and getting him to trigger his thought processes was really helpful" Mother 1

The group dynamic

All parents of children who received CO-OP within a group felt that "the pros outweighed the cons" in regard to the group format.

Being around other kids and parents

Parents felt that children, as well as parents themselves, generally enjoyed the social aspect of the group, and that being around others facilitated opportunities for child role models or mentors and provided children with inspiration and motivation. Parents

noted that ideally, groups would be made up of children of similar ability level, age and interests to maximize the experience.

"I think actually a group is a good idea, I know in the ideal world, you would have kids of similar ages and abilities. . . Because I think if you have six girls who are all working on tying their hair or using cutlery, I think they can all learn a lot from each other". Mother 1

Parents felt that at times it was powerful to work on things together and have "shared success", and that the group enabled children to try the goals of others, which was both fun and motivating. One mother noted that when her child observed others within the group attempting a task, some of whom had a more severe disability than herself, she was more willing to attempt that task. Whilst others felt it was beneficial to have children who were more capable in the group.

"I don't think you can discredit what a group can do for the kids". Mother 6

In contrast, some parents empathically perceived that it could be disheartening for another parent if their child was not as capable as others within the group.

"The group dynamic, that can really change things, because if he was in with another child who just had a little bit of a limp, and whose handwriting wasn't that great to read . . . that might have got me down a bit" Mother 4

Parents discussed the challenging dynamics of parent to parent interaction within the group, including at times that other parents lacked understanding and could be judgmental.

"The judging I found hard. I think some parents just need to sit back and don't judge until you've walked in someone else's shoes" Mother 5

In contrast, some parents felt that having another parent within the group that they could "relate to" and "personalize things" with was a real support as a parent.

It means less one-on-one therapy

All parents recognized that CO-OP within a group meant that their child received less one-on-one time with the therapist. Most parents felt that time not spent one-on-one with the therapist, when working on individual goals, was less worthwhile.

"When she had the one on one with the handwriting that's when it all clicked" Mother 5

Some parents felt that there were times during the group that they felt like they were waiting for their turn with the therapist, and not really sure what to do during these times. One parent felt that her child's motivation was poor when not directly engaged with the therapist, which in turn made this parent feel "flat".

Interestingly, the parent of a child who received one-on-one CO-OP (i.e. a group which turned out with only one participant due to randomization) stated a preference for individual sessions over the option of a group format.

Recommendations – how it could have worked better

Parents made a number of suggestions for changes they felt may be beneficial for future CO-OP groups with children with CP. All parents felt that groups would be maximized if the participants were of similar age, ability and who sought to achieve similar goals.

"If there was a group that was at a similar standard or a similar level, a group environment would work. If there's going to be quite a varied level of competence, maybe that's when one on one would be a little bit better". Mother 5

Some parents felt a smaller group, for example two children, would be beneficial, whereas one parent felt a larger group to

facilitate increased opportunities for peer interaction would be worthwhile. One parent felt that a combination of individual and group therapy could work well. Another parent suggested staggering the start time of the group so each child received more individual time with the therapists, whilst maintaining the benefits of the group. One parent of an older child felt that one week of CO-OP rather than two weeks would have enabled goal achievement, whereas the majority of parents felt that the full two week program was needed to "consolidate and transfer" CO-OP skills. A parent also felt that videotaping children carrying out their goals at the beginning, and then at the end of the CO-OP program, to enable children to see their progress would be "powerful".

Discussion

Results of this study suggest that parents of children with CP perceived that CO-OP was an effective intervention to address motor goals that involved the upper limb. Parents felt that CO-OP led to improvements in identified goals, was enjoyable and had the potential benefit of transference of the global problem-solving strategy to the child's future goals. The feasibility of CO-OP in this population appears promising,^[10,11] however, there currently exists no high level evidence to support the effectiveness of CO-OP for children with CP. Further research is needed to confirm the perceived benefits of CO-OP.

Intensity of therapy was recognized as important by parents of this study. This is consistent with a recent systematic review which suggested the most important component of upper limb task-specific training may be the intensity, and dose of therapy, rather than the specific task-specific training approach chosen.^[1] Parents in this study reported that they felt the intensity of therapy was a critical component in the successful outcomes they perceived. They felt that daily therapy over a two week period increased motivation to practice outside of the therapy setting and led to rapid achievement of chosen goals.

A child's personality traits, or personal attributes, have been recognized as important to the child's therapeutic outcomes.^[22,26,27] In particular, "self-determination" and "mastery motivation", that is, a child's intrinsic desire to succeed at a task, for the intrinsic feeling of success, rather than an external reward, may be important.^[28] The results of this study suggest that parents also recognize the importance of individual child attributes, however, do not feel they necessarily have control over preexisting child traits such as motivation and attention. CO-OP, in essence, aims to maximize motivation through the use of child-chosen goals.^[9,28] In addition to maximizing motivation, it is important to identify individual attributes, such as age, diagnosis, cognition and manual ability that may lead to success in CO-OP. This has been explored in relation to other upper limb interventions,^[29] and would be worthwhile to explore further in future CO-OP research.

Another important theme to emerge from this research was that of the challenges and contradictions that parents face when parenting their child with a disability, including the paradox of "wanting to do everything" for their child, whilst also wanting their child to become independent. This is not a new theme in the literature.^[30,31] Parents in this study found it difficult to step back and allow children to take control, at the same time as recognizing how powerful it was to hand control over to the child, and facilitate the child to become more independent. Interestingly, parents felt that being present for the CO-OP sessions facilitated this change in parenting style, although the original CO-OP protocol does not necessarily involve parents in this process.

Overwhelmingly, parents identified the importance of group participants being of similar age, ability and having common interests

in order to maximize the group experience. The use of CO-OP groups in practice should take this into consideration. The challenges of CO-OP within a group format have been discussed in children with developmental coordination disorder (DCD) [32] and appear consistent with the experience of parents of children with CP. It is interesting perhaps that the one parent in this study whose child received individual treatment, had a preference for individual treatment, whilst parents involved in the group had a preference for group treatment. In line with previous findings,[31] this may suggest that parents perceive whichever treatment has been received as an effective and preferable one.

It is important to recognize that in this study, CO-OP was not provided within its original form of individual sessions provided once per week.[9] Although the authors sought to remain true to the essence of CO-OP, in line with the CO-OP fidelity checklist,[33] this program differed from the original protocol in that it was provided to children within a group context, daily on weekdays over two weeks, with parents involved in each session.[21] It may be important, in practice, to be able to adapt treatment approaches to align with available healthcare and individual resources as long as the main traits of the approach are adhered to.

Limitations

There were a number of limitations to this study. The therapist that provided treatment was also the researcher that conducted interviews with parents, which may have impacted on the feedback given by parents. The sample size of this study was small, and the results of this paper reflect the perspectives of those parents involved in the CO-OP groups specific to this study, and cannot be applied more broadly. Although parents perceived CO-OP to be effective, it is important to combine parent perceptions of CO-OP with objective measures of outcomes to guide its implementation in this population, and the authors plan to publish results of the larger trial [21] once complete.

Conclusion

CO-OP has exciting potential for children with CP. Parents in this study identified that children enjoyed CO-OP, achieved their goals within a short time-frame and had learnt a transferable "life-skill". The intensity of this treatment, the child's motivation and the ability of parents to "step back" were identified as important factors in success. Further research to investigate CO-OP in this population, and the attributes of children who are most likely to respond to this treatment approach, are warranted.

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