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Case Report

Supporting Functional Goals in Spinal Muscular Atrophy: A Case Report of The Cognitive Orientation to Daily Occupational Performance (CO-OP) Approach

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Abstract: Children with spinal muscular atrophy (SMA) are now living longer as a result of advancements in pharmaceutical and medical interventions. There is a paucity of research regarding therapeutic interventions to support this population to be independent and participate in life activities that are most important to them. The aim of this case report is to explore the use of the Cognitive Orientation to daily Occupational Performance (CO-OP) approach to support a child with SMA type 1 to achieve their functional and participation goals. This is a retrospective case study. A 7-year-old girl with SMA type 1 received ten 1 h sessions of CO-OP, weekly in the home and community settings with a physiotherapist. Clinically meaningful improvements were found in goal performance and satisfaction on the Canadian Occupational Performance Measure (COPM) and Performance Quality Rating Scale (PQRS). Despite the progressive nature of SMA, the CO-OP approach was able to support goal attainment. Given medical advances are leading to a longer life span for children with neuromuscular conditions, further research is needed to investigate the efficacy of functional and participation-based interventions, including impact on quality of life and self-efficacy.

Keywords: cognitive approach; CO-OP; neuromuscular; rehabilitation; paediatric; physiotherapy

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1. Introduction

Children with spinal muscular atrophy (SMA) are now living longer due to life-changing advances in medical technology [1]. Therapeutic interventions have not kept pace, with little evidence to understand how allied health clinicians can best support children with SMA to be independent and participate in the activities that are most important to them [1,2]. Effective interventions to support children with SMA who are now living longer need to be explored.

SMA is an umbrella term for a group of degenerative neuromuscular conditions characterised by a progressive loss of muscle strength and motor function [1]. The most common cause of SMA is as a consequence of a defect in the survival motor neuron gene (SMN1) leading to muscle atrophy, weakness and paralysis [3]. Prior to the genetic basis of SMA being understood, SMA was classified according to five phenotypes based upon the age of onset and maximum motor function [3]. SMA type 1 is the most severe and common subtype in living patients with an onset usually in the first 6 months of life. SMA type 1 accounts for 60% of all children with SMA and is the most common genetic cause of death in infants, and until recent medical advancements, life expectancy was 2 years of age [3]. Typically, children with SMA type 1 depend on powered wheelchairs to mobilise, are dependent on gastrostomy tubes for feeding, suffer from progressive scoliosis and joint contractures, and are highly vulnerable to respiratory infections [4]. Although children with

SMA require a significant level of physical support, many children have normal to above-average cognition [3,5,6]. Children living with degenerative neuromuscular conditions such as SMA have limited control over their surroundings, have difficulty performing activities of daily living and have a lower health-related quality of life (HRQOL) [7]. This is compounded by the reality that their function only worsens over time.

There is currently limited published evidence regarding interventions that can support client-centred goal achievement and rehabilitation for children with SMA, despite increased survival rates and reduced morbidity due to medical advancements [8]. Current guidelines for SMA focus predominantly at the impairment level of the International Classification of Functioning, Disability and Health (ICF) [2]. These guidelines include stretching (including orthotics and bracing), positioning, mobility and exercise, with a focus on adaptive equipment and assistive technology, and chest physiotherapy [1]. There is very little evidence to support therapeutic practice for children with SMA type 1 [1], with this research gap highlighting the need for further research regarding interventions that can support children with SMA to carry out the activities that are most important to them.

Detrimental effects on quality of life, for those with severe physical impairments, are thought to be a consequence of environmental barriers and inequity of opportunity rather than the impairment itself [9]. A recent scoping review explored the use of assistive technology in patients with SMA type 1 to enhance activity and participation [8]. Only four studies in this review (cohort or case series) included interventions to support activities and participation.

The Cognitive Orientation to daily Occupational Performance (CO-OP) approach is a task-specific, child-centred, cognitive approach that aims to enable children to achieve their own goals [10–12]. This approach differs from other rehabilitation interventions in that it focusses on the importance of the client having task knowledge and being able to problem-solve strategies to carry out an activity, rather than assuming that underlying impairments (such as muscle strength and joint range of motion) need to be addressed to achieve functional goals [11,12].

The CO-OP approach has been shown to be effective in a range of diagnostic groups, including, but not limited to developmental coordination disorder, autism spectrum disorder, cerebral palsy, brain injury, spina bifida and stroke [13–17]. The key elements that characterise the CO-OP approach include setting client-chosen goals, task-specific practice, guided discovery to support the child to develop their own effective strategies for successful task completion, and sufficient repetition and practice to bring about change [12]. When considering which clients the CO-OP approach may be appropriate for, client prerequisites include the following: (1) the ability to identify three goals, (2) the ability to have sufficient language and cognitive skills for strategy and plan generation, (3) the ability to attend and respond to the task and the therapist, (4) the potential ability to perform the task and (5) the motivation to learn and practice [11,12].

Children with degenerative neuromuscular disease are often steered away from difficult tasks by caregivers as it is felt that they lack the ability to physically perform the task. Children with SMA generally have effective cognitive and language skills and have had to modify tasks their whole life in order to maintain independence. Given the focus of the CO-OP approach on problem solving rather than underlying impairments, and the strengths of those with SMA, the CO-OP approach is a theoretically valid intervention in this population.

There is a substantial practice and research gap for children with SMA, with few intervention options to support functional improvements and child-centred goal attainment in this population. Given the benefits of the CO-OP approach in other populations, exploration of this intervention in SMA and other neurodegenerative conditions is warranted. To our knowledge, there are no prior case reports or research studies that explore the use of the CO-OP approach in SMA. The aim of this case report was to explore the use of the CO-OP approach to support a child with SMA type 1 to achieve their goals.

2. Materials and Methods

A retrospective case report was used, and low-risk ethical clearance was granted (HNELHD HREC AU202211-04, 8 November 2022). Pre- and post-outcome measure data were collected as part of the intervention protocol. Results have been combined with therapist reflections used to highlight the experience of the participant during the intervention.

2.1. Participant

'Miss M' (client-chosen pseudonym) is a 7-year-old girl with a diagnosis of SMA type 1. She lives with her parents and two younger siblings in regional NSW, Australia. She is fully dependent on her parents and carers for all of her personal activities of daily living and requires the support of a two-person assist for all mobility transfers via a sling hoist. Miss M utilises a powered wheelchair for mobility within the home, in the community and at school. Miss M requires the support of a thoracolumbar sacral orthoses to enable her to sit independently, is unable to roll between her stomach and back, and is dependent on carers for her floor mobility. Miss M requires a percutaneous endoscopic gastrostomy (PEG) tube to support her to maintain adequate nutrition. Miss M attends a mainstream school for education and has no identified communication or intellectual concerns.

2.2. Outcome Measures

As a measure of self-rated goal attainment, the Canadian Occupational Performance measure (COPM) was used. This is part of the CO-OP protocol and asks the individual to rate both their perception of the 'performance' of the goal and their 'satisfaction', i.e., how happy they are to be able to perform the skill at that level, on a 10-point rating scale, with 1 being the lowest and 10 the highest. The COPM is structured as a client-centred interview and is validated to capture change over time [18]. This tool demonstrates good test–retest reliability and validity, and is a sensitive tool to detect change in the paediatric rehabilitation population [19] with a change score of 2 to 3 points representing a clinically meaningful effect [20,21].

The Performance Quality Rating Scale (PQRS) is an observational performance measure, used in conjunction with the COPM for the therapist to rate the child's actual rather than perceived performance [22]. The therapist rates the child's performance on the three child-set goals on a 10-point scale. The PQRS scale has been deemed reliable and has good internal responsiveness in children diagnosed with developmental coordination disorder [22].

For this case, the COPM and the PQRS were carried out at the first session, then after completion of the 10 weeks of intervention. Miss M rated her own performance and satisfaction on the COPM and was not provided with previous scores at the end of intervention assessment in an effort to reduce bias.

2.3. Intervention

The CO-OP approach is a protocolised intervention that has been described in detail [11,12] and replicated in research across a range of diagnostic groups [23]. The CO-OP approach is a client-centred, goal-focussed intervention that utilises cognitive strategies and whole-task practice. The CO-OP approach has been found to lead to goal achievement through a lower dose of intervention compared to other task-specific rehabilitation interventions [24].

The CO-OP approach was chosen for Miss M as she had specific functional goals she was hoping to achieve, she met the pre-requisites for CO-OP and the therapist felt Miss M would respond to the cognitive strategies included in this approach. The CO-OP approach [11,12] was provided individually on a weekly basis within the context of the client's home and community. The therapist providing the intervention was a physiotherapist, recently trained in the CO-OP approach.

In the CO-OP approach, clients identify the goals that are most important to them. The cognitive strategy of GPDC is then introduced to the client, and the therapist supports

plan generation through dynamic performance analysis and guided discovery. Goal performance is rated at the beginning and end of the intervention using the COPM and PQRS.

During the first session, Miss M identified three activity and participation-based goals that they wished to achieve and was then asked to rate their current level of performance and satisfaction for all three goals utilising the COPM. The therapist rated their baseline level of performance using the PQRS in this same session.

During the initial session, the global metacognitive strategy of 'Goal–Plan–Do–Check' (G–P–D–C) was introduced using visual flip cards and a letter pneumonic. As Miss M was learning spelling within their school syllabus at the time, the use of the pneumonic G–P–D–C and the visual prompt for the start of each word were motivating for the child. To improve engagement and buy-in, and in alignment with the child's competitive attributes, a game of memory was then introduced, whereby the child needed to correctly flip the cards in the correct order.

The subsequent 10 sessions were carried out in the home and community context, as this is thought to enhance generalisation and the transfer of skills [17]. The sessions focused on the key principles of CO-OP including utilisation of the global strategy G–P–D–C, dynamic performance analysis and guided discovery to enable strategy generation. Dynamic performance analysis involved active observation-based exploration of Miss M performing their goals, with the therapist then using guided discovery to engage the child to actively problem solve and uncover their own strategies and plans. Each session began with a focus on one goal (of Miss M's choice) and then moved onto the next goal within the same session once the child had adequately developed a new strategy or demonstrated signs of fatigue for this goal. Open-ended questions were used to stimulate individual strategy generation. Miss M responded well to 'taking the lead' and control of the session, and the notion of 'coaching not adjusting' was used to guide her.

3. Results

Miss M was able to participate in the CO-OP approach.

Miss M identified the following goals (using her own words):

1. "I want to play handball at recess and lunch with my friends"
2. "I want to play wheelchair basketball"
3. "I want to race at the cross-country carnival like the other kids in my class"

Results of pre- and post-COPM and PQRS scores are provided in Table 1. The average pre–post-change score across her three goals for COPM performance was 5; for COPM satisfaction, this was 5; and for PQRS, this score was 5.4, as shown in Figure 1. These improvements represent clinically significant changes in average goal performance and goal satisfaction.

Table 1. COPM and PQRS measures, pre-and post-CO-OP intervention.

Goal	Pre-Intervention Score	Post-Intervention Score	Change Score
Handball			
COPM Performance	5/10	6/10	1
COPM Satisfaction	1/10	6/10	5
PQRS	2/10	6/10	4
Basketball			
COPM Performance	1/10	10/10	9
COPM Satisfaction	1/10	6/10	5
PQRS	1/10	5/10	4
Cross-Country Running			
COPM Performance	5/10	10/10	5
COPM Satisfaction	5/10	10/10	5
PQRS	2/10	10/10	8

COPM = Canadian Occupational Performance Measure; PQRS = Performance Quality Rating Scale.

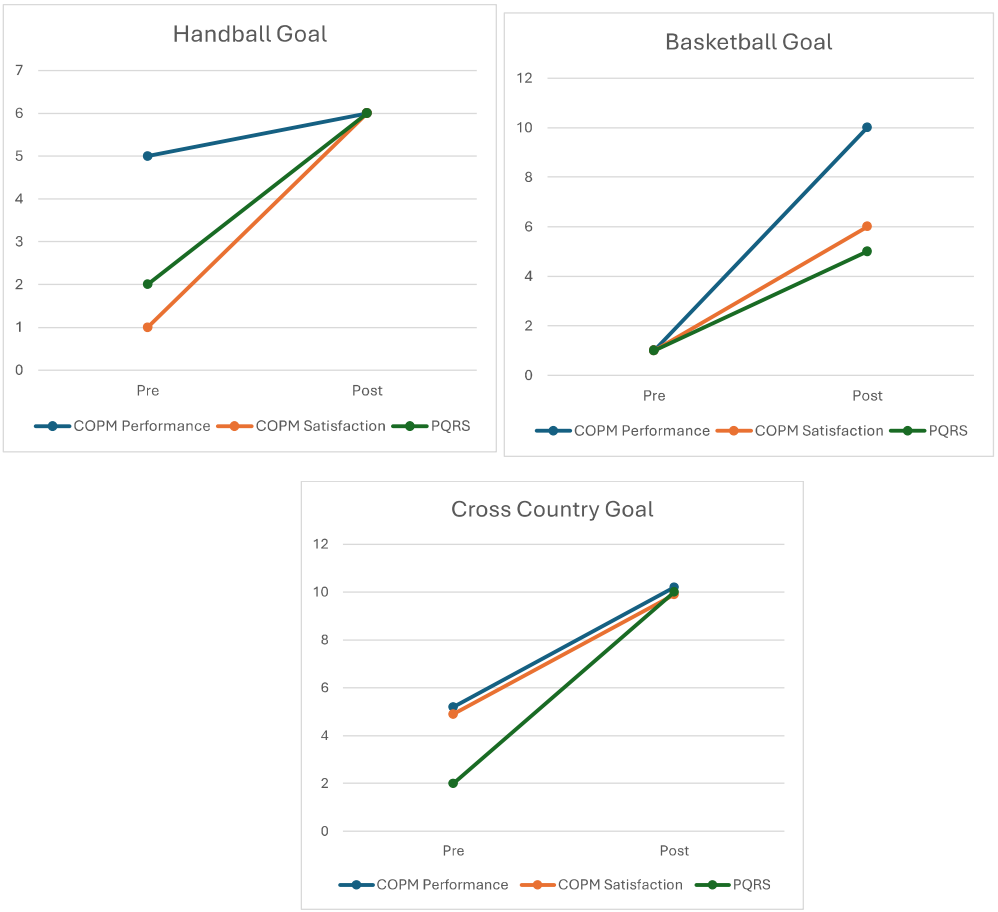

Figure 1. Before–after goal scores on COPM Performance, COPM Satisfaction and PQRS.

Miss M responded very positively to 'taking the lead'. During intervention, the therapist observed that Miss M thrived on the opportunity to set her own goals, and this process enabled Miss M to identify goals that she had previously not been given the opportunity to attempt. Previously, it had been Miss M's parents who had chosen the focus/goals of intervention.

Miss M's effective communication and problem-solving skills meant that participation in the CO-OP approach focussed on her strengths and enabled her to lead her therapy, which was different to previous interventions she had participated in. Whilst she had spent her whole life on the receiving end of therapy and being defined by her physical limitations, the CO-OP approach appeared to intrinsically motivate her by allowing her to 'be the therapist' and dictate her proposed solutions to each of the problems in front of her. The focus emphasised that it was not her lack of ability that hindered any progress, but rather 'the plan' that needed modification prior to success. This change in focus appeared to be positive for both Miss M and her family and carers.

Through the process of guided discovery, the development of "domain-specific strategies", individualised to Miss M, were generated. In the CO-OP approach, domain-specific strategies are smaller plans or strategies specific to the individual, task and situation that guide the successful performance of the proposed goal. A list of the domain-specific strategies for the goal of "I want to play handball at recess and lunch with my friends" are provided in Figure 2.

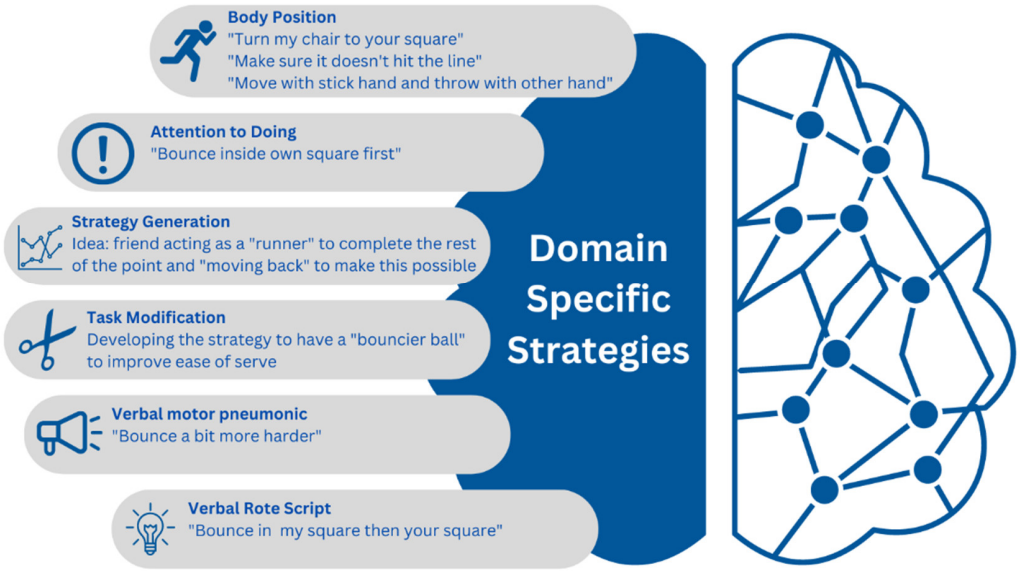

Figure 2. Domain-specific strategies used in this CO-OP case study.

Domain-specific strategies were written down as a homework reminder for Miss M and discussed with her carers and parents for practice between weekly therapist-led intervention sessions. Caregivers were involved throughout the intervention period to ensure the salient features of the CO-OP approach were understood and could be transferred into daily life through the use of enabling principles. The therapist observed that both Miss M and her family enjoyed the CO-OP process and Miss M loved having control over the focus of therapy. A recap of performance, including exploration of successes and challenges, and execution of the global cognitive process from the week before with caregivers and the Miss M was performed prior to each intervention session.

In addition to cognitive strategies, the therapist utilised the key components of the CO-OP approach throughout the intervention, including enabling principles, dynamic performance analysis and guided discovery. Examples of enabling principles used with Miss M are provided in Table 2.

Table 2. CO-OP enabling principles and how these were utilized with Miss M.

Enabling Principles	How Therapist Used Enabling Principle with Miss M
Make it fun	Being motivated to practice the goal of handball with carers and siblings and Miss M's competitive nature to do so facilitated a continuous playful interaction throughout the problem-solving process between caregivers, therapist and the child.
Work towards independence	Miss M thrived with independence and taking the lead. They were eager to demonstrate their independence in use of the cognitive process through 'homework' recaps of their use of the 'Goal–Plan–Do–Check' and bringing back progress videos of their performance of handball at school each week to show the therapist.
Promote good strategy use	Supplementing task knowledge of school handball games and wheelchair soccer was utilised in order to enable effective strategy generation. Collaborating with the school sport's teacher and principal allowed for further support of Miss M's strategy generation and guidance.
One thing at a time	Only one performance breakdown was focused on at a time and the sequence of the activities were prescribed and lead by Miss M. When the therapist or caregiver felt that Miss M's motivation was waning or they had reached their maximum strategy generation and required periods of consolidation, they would guide the child to progress onto their next goal.

Guided Discovery was used throughout, and Miss M thrived on coming up with and discovering the solutions and strategies themself. The relative vulnerable and dependent nature of Miss M's neuromuscular condition may have contributed to this positive response

as Miss M was previously used to being so dependent on others for her day-to-day activities. Meichenbaum's scaffolding techniques and mediational techniques of Feuerstein [11] guided these processes through strategies including 'ask don't tell', 'guide, don't adjust', 'make it obvious' and 'bridge beyond'.

Task knowledge was an important consideration for Miss M, and the CO-OP approach highlights that one must have at least rudimental task knowledge to be able to carry out a valid performance analysis [25]. For Miss M, supplementing task knowledge was needed for her goal of playing handball with her friends. In order to supplement knowledge, video and photos were taken of the handball court in the school environment with peers demonstrating the rules of handball.

4. Discussion

This case report has shown that the CO-OP approach can be effective in enabling a child with SMA type 1 to achieve their functional goals relating to activity and participation in daily life. Miss M enjoyed being able to set her own goals and was able to effectively utilise the problem-solving strategies within the CO-OP approach to come up with solutions to her goals of playing handball, basketball and participating in the school cross-country race.

The current guidelines for children living with SMA have a primary focus at the impairment level of the ICF [1]. Yet, it is believed that the ability to coordinate ones' own activities in life creates a sense of control, and that it is the persons control over his or her performance of activities that is integral to their quality of life [9] and self-efficacy. There is currently very little evidence to guide interventions targeted at improving participation for children with SMA. The CO-OP approach may be one intervention option that could improve self-efficacy and support individual goal achievement in those suffering from neuromuscular disease, and this case study has shown that further research regarding participation-based interventions, such as the CO-OP approach, may be warranted.

The CO-OP approach is child centred, through both the process of child-directed goal setting and throughout the collaborative intervention process. The CO-OP approach, with its focus on self-efficacy, may give children with neuromuscular conditions the ability to have a voice and make decisions about interventions that concern them, with a focus on activities and participation in their day-to-day life. SMA type I is the most severe subtype of living patients with the disease and is associated with the lowest quality of life, as measured by caregivers on the Pediatric Quality of Life Inventory 3.0 Neuromuscular Module (PedsQL NMM) [26]. The case report subject, Miss M, demonstrates specific disease-related characteristics (e.g., poor mobility, disease instability, severe scoliosis requiring surgery, digestive system dysfunction and respiratory support) that were associated with lower scores on the on the PedsQL NMM and the Paediatric Quality of Life Inventory Family Impact Module (PedsQL FIM) [26]. The use of the CO-OP approach in this population group, may enable support through coaching to increase personal capacity, teaching adaptation and problem solving of environmental barriers to enable goal success.

The level of a child's motivation to carry out interventions has been identified as an essential independent variable to determine the success of therapeutic interventions [27–29]. This element is potentially intrinsic in children with progressive neuromuscular conditions as utilising the strategy generation in the CO-OP approach and self-generation of goals enables them to improve their locus of control. This was certainly the case for Miss M. She loved being able to set her own goals and thrived on the opportunity to take control of her own therapy sessions and come up with her own solutions to achieve goals. Previous studies suggest that children setting their own goals fosters improved motivation for mastery and that it gives children greater control over their therapy [27,30]. Miss M's goal of participating in a cross-country race is a great example of a goal that therapists and carers might discourage a child from setting, as it may be assumed the child would not be able to independently perform this task. However, Miss M problem solved a solution that involved her sports teacher running her in her beach wheelchair; Miss M's perception of successful goal performance was quite different to what therapists and carers may have assumed. In

this instance, 100% satisfaction and performance were achieved by Miss M. This was a great example of the positive impact of empowering children to set their own goals and come up with solutions that work for their individual needs and desires. Although Miss M did not physically perform the skill independently, she was able to participate with her friends and achieve her goal.

An additional potential benefit of the CO-OP approach, compared to other interventions, is the possibility of generalisation and transfer. 'Generalisation' is the notion that once the activity is learned, it can be applied to new contexts and 'transfer' is the idea that the global cognitive strategy or individual domain-specific strategies can be applied to solve activity and participation restrictions in the future. It has been shown that the improvement in executive function via the improvement of problem-solving skills can be used for future goal success and independence in functional skills outside of therapy [31].

Given the improvement in Miss M's goals, the CO-OP approach shows promise for individuals with more severe neuromuscular disease, although this single case report cannot be generalised to others. Further research is needed to see whether, once learned, the activities and performance can be maintained and transferred into other areas. Further research is needed to explore whether the CO-OP approach is effective in others with neuromuscular conditions, whether generalisation and transfer can be achieved and whether the CO-OP approach can improve the sense of control and health-related quality of life for children with neuromuscular conditions.

The use of goal-directed interventions that involve active practice in this population may lead to additional benefits such as those seen in exercise training. Although exercise training is often a point of debate in neuromuscular disease, early studies have shown that such training can activate recovery motor neurons to improve motor function and quality of life in patients with degenerative neuromuscular disease such as Duchenne's muscular dystrophy and SMA [26,32]. The CO-OP approach has shown that motor neuron recovery is most effective when tasks are meaningful, and it would be helpful for future research to compare traditional exercise training approaches to task-specific training and cognitive-based motor training interventions. Advances in pharmaceutical management now mean that children with SMA type 1 are surviving longer, and the field needs to now understand how therapeutic interventions can best support this population.

Goal-setting measures such as the COPM [18] are valid and reliable paediatric goal-setting measures in the neurological disease population. In degenerative neuromuscular conditions such as SMA, it is also important to note that an individual may actually experience a reduction in task performance over time given their deteriorating motor function, so it is important for outcome measures and measurement of intervention efficacy to take this into consideration.

Caregivers of those with SMA become experts on their child's management, yet caregivers of those with palliative conditions or complex chronic disease such as SMA still express the need for more education and support from their relevant healthcare team in order to manage care [33,34]. Parental and caregiver involvement is an integral aspect of the CO-OP approach and allows for the generalisation and transfer of improvement to other areas of the child's life. The enabling principles and guided discovery strategy generation in the CO-OP approach provide parents with another tool to empower their child to increase their independence. Previous research has demonstrated that when children are shown self-management skills, it can result in improved disease-related outcomes [35,36] and improved self-efficacy, reducing one's perception of disease burden and improving quality of life [37,38].

This study has limitations. This was a single clinical case that was retrospectively presented to show the benefits of the CO-OP approach in this population; therefore, the results cannot be generalised to others with SMA. Future studies should include more rigorous research designs, that can more explore the benefits of an intervention in rare conditions. It may also be important for future research to be of a qualitative nature to include the patient experience.

5. Conclusions

The CO-OP approach was able to be used with a child with spinal muscular atrophy to successfully achieve meaningful participation-focussed goals. Future research is needed to explore whether the CO-OP approach is helpful for others with neurodegenerative conditions. Clinicians are encouraged to set meaningful goals and consider interventions that focus on participation when working with children with neurodegenerative conditions such as SMA.

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Informed Consent Statement: Informed consent was obtained from all subjects involved in the study. Written informed consent has been obtained from Miss M's caregivers to publish this paper.

Data Availability Statement: Further data can be obtained from the authors.

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Conflicts of Interest: Iona Novak and Michelle Jackman are ICAN-certified International CO-OP trainers and thus acknowledge a conflict of interest that may influence their interpretation of the findings.

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