

# Perspectives of people with Parkinson's about Cognitive Orientation to daily Occupational Performance (CO-OP)

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## Background

Parkinson's disease (PD) is the most rapidly increasing progressive neurological condition worldwide, with projections estimating over 17 million cases by 2040. Although advancing age is a major risk factor PD can occur at any stage of life and results in prolonged and progressive disability. Around 90% of people with PD experience psychological challenges which can include sleep disturbances, cognitive impairment, anxiety, and fatigue. These psychological challenges typically appear early, are hidden, and often have a more profound impact on quality of life (QoL) than motor symptoms. Current literature lacks clear guidance on addressing the complex and varied symptom profiles of individuals with long-term PD. There is a clear need for comprehensive, person-centred interventions that enhance participation and improve QoL.

The Cognitive Orientation to daily Occupational Performance (CO-OP) is a well-established intervention that combines functional skill development with metacognitive strategy training. It addresses both motor and psychological challenges that impact participation and QoL by equipping individuals with structured problem-solving techniques to improve performance in personally meaningful goals. CO-OP has shown positive outcomes across various neurological conditions, including traumatic brain injury, stroke, spina bifida, and cerebral palsy. Despite promising evidence in related populations, CO-OP has not been thoroughly evaluated in PD.

To address this gap, we conducted a randomised controlled feasibility trial (RCT) with a nested qualitative study capturing the experiences and perspectives of individuals with PD. The RCT assessed the feasibility and preliminary impact of CO-OP in PD. The qualitative study focused on how participants perceived the intervention, its relevance to daily life, how they applied the strategies taught and potential adaptations needed to optimise the approach for this population. The trial was based on the rationale that a comprehensive approach that encompasses both motor and non-motor symptom management for people with PD may lead to important physical, cognitive, emotional, and social functioning impacts. The study was approved by the UQ Human Research Ethics Committee (HREC) - 2020/HE002650 on 9 February 2021.

## Design and Methods

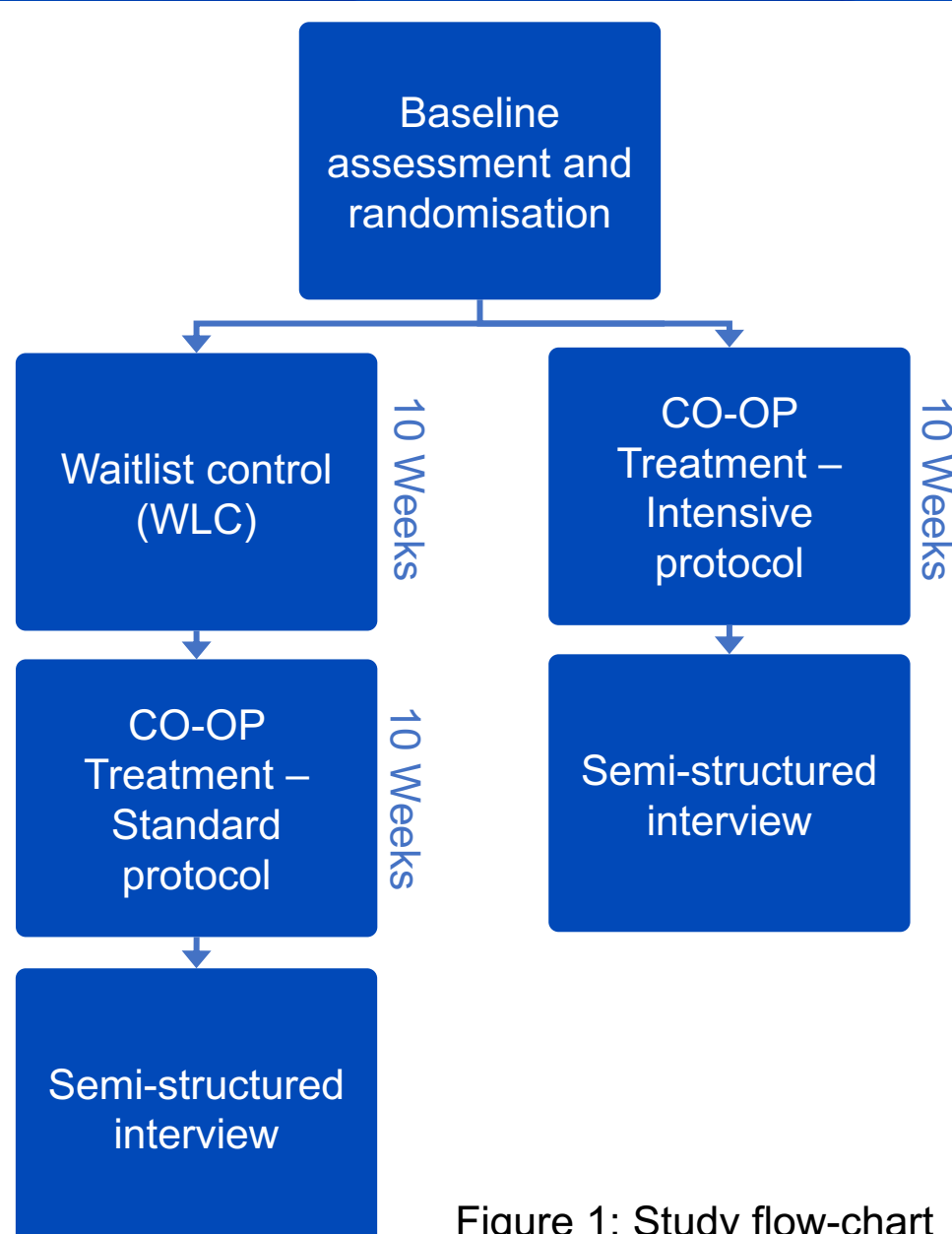


Figure 1: Study flow-chart

### Procedures

Following the baseline assessment and goal setting, participants were randomised to either the CO-OP treatment group or a WLC. CO-OP training was carried out one-to-one by a CO-OP-certified occupational therapist in participants' home environments. The intervention group received the intensive protocol (2 x 1-hour CO-OP sessions/week = 20 sessions) for the 10-week intervention period. The WLC group had a non-intervention period of 10-weeks before receiving the standard intervention protocol (1 x 1-hour CO-OP session/ week = 10 sessions) for the 10-week intervention period. The manualised CO-OP program was followed to ensure consistency between participants and within intervention conditions.

### Interviews

Semi-structured interviews were conducted. An interview guide was developed, and therapist field notes were used to probe participant's unique experience of the CO-OP intervention. Interviews were recorded and transcribed verbatim. The interviews ranged from 16-40 minutes.

## Analysis

Interview data were analysed using inductive, reflexive thematic analysis. Two researchers first familiarised themselves with the transcripts, then independently coded a subset of five interviews. All coding decisions were recorded in an audit trail. LA then coded the remaining transcripts, which were reviewed by SD. Together, LA and SD refined the coding framework. Codes were grouped into categories, and themes were collaboratively generated through consensus meetings involving all researchers. A thematic map and visual summaries were iteratively developed to ensure the themes accurately reflected the full data set. Participant quotes were selected to clearly represent the core themes and lived experiences.

## Results

**Sample size, *n*:** 20

**Age in years, *mean (SD)*:** 67.25 (7.76)

**Male/Female:** 9/11

**Duration of PD in years, *mean*:** 5.65

**Hoehn & Yahr Stage:** Stage 1=2, Stage 1.5=5, Stage 2=3, Stage 2.5=3, Stage 3=6, Stage 4=1

**Addenbrooke's Cognitive Evaluation-III, *mean (SD)* range:** 94.3 (5.44) 78 – 99



Figure 2: Thematic Map Detailing Relationships and Temporal Aspects from Analysis

**Theme 1.1:** *“I think the CO-OP treatment approach is good because it’s giving me tools to work towards the goal and that’s really important for me because I often jump ahead and do things, trying to discover how to make them myself but I find I do need the structure of the plan. Goal, plan, do, check. I’ve been the type of person to have a goal and then do it really badly. And yeah, I think it’s good to have that format to remember that.”* (P12, H&Y 3)

**Theme 1.2:** *“You’re in your own home, so you are more relaxed, but it’s also more meaningful because as the therapist came at different times, there might have been something that I found difficult during the week and I can - instead of having to talk about it, which can become more difficult, I can actually show her what the problem is and we can work through and find a solution.”* (P18, H&Y 2)

**Theme 1.3:** *“I like the way you offered suggestions. You shared your experience, which was really helpful. I felt comfortable with you so that I could be very honest without upsetting you or anything else like that.”* (P8, H&Y 1)



## Results (continued)

**Theme 2.1:** *“I think what’s happened is it’s given you a belief in yourself that you can minimize the impact of this problem. I think it’s been beneficial from the point of view; it’s given me more confidence, that you kind of, you know, you improve more and more and more.”* (P17, H&Y 2)

**Theme 2.2:** *“I think it’s helped me to understand that I do have the ability to think things through, to plan how to manage a situation or a particular thing I want to achieve. And I’m confident that’s going to help as things deteriorate down further.”* (P7, H&Y 1.5)

**Theme 2.3:** *“The program has helped me to realize that you know that I can actually do the things I want to do... it’s reinforced the fact or given me the confidence to say, to do, to have a go at it, rather than not do it because of embarrassment or whatever else it is. It’s helped me to look, not accept, look at and be more aware of the self in a way.”* (P7, H&Y 1.5)

**Theme 3.1:** *“Prior to doing this intervention, I would start 10 things during the day and finish none of them. And now I’m like, I still have 10 things in the list, but it’s in a list and sometimes I’ll get eight, seven, six, eight and normally at least half. It’s things that I thought I’d never get around to doing. Now, it seems possible.”* (P3, H&Y 3)

**Theme 3.2:** *“the good parts of life are more frequent. I take more time to do things I enjoy. I feel that I’ve made some good steps appreciating and engaging in interpersonal relationships better. I definitely feel that my day-to-day life has been impacted by these things.”* (P1, H&Y 2.5)

**Theme 4.1:** *“I’m less concerned about some of the things, or any of the things, that set goals for. I’m not worried about those anymore. I think I can even transfer that through. I’m pretty confident that, if something comes up, I’ve got to use that process to put it into manageable pieces.”* (P7, H&Y 1.5)

**Theme 4.2:** *“I need it now to be able to feel some sense of achievement. I think it’s a good method of being able to do some day-to-day things that we take for granted”* (talking about metacognitive strategies in CO-OP).” (P15, H&Y 1.5)

## Discussion and Conclusion

This study explored how people with PD experienced the CO-OP approach, how they learned and applied its strategies, and how it influenced their daily lives. Four key themes emerged:

**Key aspects of CO-OP:** Participants valued three core components—metacognitive strategies, therapy in the home, and therapist actions and qualities. The structured “goal-plan-do-check” method helped participants manage cognitive challenges and improve daily function. The home setting was seen as more relevant and accessible, especially for those with mobility or cognitive difficulties. Therapist qualities aligned with person-centred care, and participants appreciated individualised, goal-based support—an aspect they felt was often lacking in traditional PD care.

**Increased Self-Awareness:** CO-OP enhanced participants’ awareness of their abilities and how to adapt to life with PD. This self-awareness was viewed as foundational to building self-efficacy, confidence, and acceptance of their diagnosis. These internal shifts were key enablers of external improvements.

**Broad Functional Benefits:** Participants reported improvements in daily tasks, social engagement, and participation. CO-OP was perceived as effective across multiple areas of life, aligning with evidence that metacognitive strategies support rehabilitation beyond symptom-specific interventions.

**Sustained Use for Continued Benefit:** The success participants experienced led to a desire to continue using CO-OP strategies after the intervention ended.

This study offers early evidence supporting the perceived benefits and effectiveness of the CO-OP approach for people with Parkinson’s disease. Although the ideal intensity and duration of CO-OP has not yet been established, participant responses highlights the value of tailoring intervention length to individual needs, such as goal complexity and symptom severity—providing useful guidance for clinical implementation. Further research is required to confirm CO-OPs effectiveness in this population. Nonetheless, these findings enhance our understanding of how metacognitive strategies can support ongoing adaptation in daily life, potentially leading to sustained benefits for people living with PD.