



A cognitive occupation-based programme for people with MS: acceptability, feasibility, and experiences of people with multiple sclerosis

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The authors have no conflicts of interest to report.

Trial registration

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Abstract

Purpose: COB-MS is an eight-session, Cognitive Occupation-Based programme for people with both MS and cognitive difficulty – designed to enhance cognition and daily functioning, through a combination of goal-setting, cognitive strategy engagement, group activities, home-practice activities and one-on-one sessions. This research aims to investigate the acceptability of COB-MS from the perspective of people living with MS, as well as the occupational therapists who facilitated the programme. **Materials and methods:** Two content analyses were conducted on interview data from (n=11) COB-MS participants and (n=8) COB-MS facilitators. Thematic analysis was also conducted on the participant interview data. **Results:** Through a, primary, content analysis, participants reported that the COB-MS provided both a positive experience and quality resources. Qualitative improvement and utilisation of their learning beyond completion of the intervention were also identified. Four themes were identified via, secondary, thematic analysis: (1) Group interaction within COB-MS was vital; (2) Online COB-MS had positive and negative effects on participation; (3) COB-MS as a provider of clarity; and (4) Using learned strategies after the completion of COB-MS. Recommendations for future administration are provided. **Conclusions:** Findings suggest COB-MS acceptability, as well as appropriateness and feasibility, indicative of progression to a definitive trial in future research.

Key words: Multiple sclerosis, Public and patient involvement (PPI), Cognition, Occupational Therapy

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1.0 Introduction

Multiple Sclerosis (MS) is a complex disease that is characterised by inflammatory demyelination and degeneration with resulting damage to the white and grey matter of the central nervous system [1,2]. It is typically reported that up to 65% of people with MS experience a decline in their cognitive functioning [3-5], with memory, executive functions, processing speed and attention being the most affected areas [6]. Cognitive difficulties associated with MS have been described as debilitating invisible symptoms and some of the most distressing symptoms of the disease [7]. Such cognitive difficulties have significant impacts on health-related quality of life, increase the likelihood of being unemployed, having depression, and having difficulty managing self-care and daily life activities [8;9]. Nevertheless, cognitive difficulties are often neglected in clinical care [10,11].

Although it is commonly occupational therapists (OTs) who assess and treat cognitive dysfunction in MS in the UK [10] and Ireland [12], there are few – if any – occupation-focused cognitive interventions to alleviate the decline in cognition for people with MS [13]. The overall evidence for cognitive rehabilitation in MS is, however, promising with short-term results (1-6 months post-intervention) in subjective memory, quality of life, verbal memory, and information processing found in a recent Cochrane review [14].

Ensuring clear reporting of intervention content and including patient reported outcomes (PROs) can help improve understanding of cognitive interventions as well as the direct impacts of interventions on particular aspects of the participants' cognition [15; 16]. PROs have limitations and they do not detect the experiential changes that are significant to the participant following such interventions [17]. Additionally, solely quantitative studies do not allow for participants to discuss points of importance that quantitative measures may miss [18] or even the subtle nuances within the trial that may otherwise be taken for granted by the researchers [e.g. see 19-21]). For instance, many quantitative studies of the PROs of cognitive

interventions do not consider non-cognitive impacts on participants, such as the effect of socialisation within group interventions on the value of the programme [22]. Qualitative methods can provide context and allow participants not only to discuss their experiences within and post-intervention, but also to provide opportunities to elaborate on their performance and responses on the quantitative measures [23]. Importantly, there can often be a mismatch between subjective and objective cognitive outcome measurement [17,22,24,25], and qualitative evaluation allows for exploration of this. In designing and developing high quality RCTs, it is important for strong preparatory work to focus on acceptability and feasibility, such as through the integration of qualitative research; rather than efficacy, per se [26,27]. Such integration also enables the research team to more readily identify and evaluate specific aspects of a trial that may otherwise be difficult to explore from an exclusively quantitative approach and facilitate better understanding of the improvements to cognition as the participant experiences them [28].

In light of this rationale, the current research presents a qualitative exploration and evaluation of a feasibility trial of the Cognitive Occupation-Based programme for people with MS (COB-MS), as described in Dwyer et al. [29,30]. COB-MS is an eight-session OT-delivered programme, designed to enhance cognition and daily functioning in people with MS living with cognitive difficulties. The intervention uses a combination of goal-setting, engagement with cognitive strategies, group activities, home-practice activities and one-on-one sessions [for further details, see (13,29)]. Thus, the aim of this research is to investigate the acceptability of COB-MS and investigate the barriers and facilitators to using COB-MS from the perspective of people living with MS, as well as the OTs who facilitated the programme – thus, informing the feasibility of COB-MS [29,30]. Notably, this qualitative research is conducted to complement concurrent research evaluating more quantitative aspects regarding feasibility of COB-MS.

2.0 Method

2.1 Study Context & Design

This qualitative study was conducted within the context of a RCT of COB-MS – a single-blind, cluster-randomised controlled feasibility trial, using a two-arm (i.e. treatment and wait-list controls) study design [29,30]. A series of semi-structured, one-on-one interviews were conducted with both intervention participants (i.e. people with MS) and intervention facilitators (i.e. OTs not part of the research team or its design) to explore the acceptability and feasibility of the COB-MS intervention. Analyses of participant and facilitator data were conducted as distinct and will be presented separately.

2.2 Participant Selection

Participants were extant (i.e. informed and consenting) participants or facilitators of the COB-MS arm of the trial [for full recruitment strategy, see (29)]. Stratified, purposeful sampling was used by an unblinded researcher (i.e. taking no part in the quantitative analysis of the trial), who created a sequential list for interview invites in light of randomly selected participants following establishment of pre-selected parameters, using low-inference variables and controlling for demographics (e.g. gender, geographic area, MS-type). Based on principles of information power [31], the sample size was pre-determined to include approximately 25% of the COB-MS intervention arm. Thus, the target sample for this qualitative study was $n = 13$ (i.e. 26%). If a participant declined to participate in an interview, the next participant in the list was contacted, in light of the aforementioned recruitment strategy, until the pre-determined sample size was reached. Declining participation in the interview had no impact on their engagement with COB-MS. Extant facilitator participants ($n=8$) were CORU registered OTs working in Ireland at the time of the trial, recruited via flyer and OT study information sheet (through professional body email [*Association of*

Occupational Therapists of Ireland] and through notification on the *MS Ireland* website, Irish health professionals email list and the bi-annual *MS Ireland* research e-zine).

2.3 Data collection

Online interviews with participants and facilitators were conducted and recorded via *Zoom Video Communications, Inc.* by the embedded patient researcher (RAJ) and the post-doctoral researcher/project manager (CPD) from the COB-MS trial, respectively. The interview questions asked pertained to, for example, overall experience with COB-MS, positive and negative experiences with the programme, suggestions for how to improve the intervention and likelihood of strategies presented in the programme to be used following the intervention. The interview guides are presented in Table 1 and, though similar, differ to reflect distinct roles as participants and facilitators. All questions are designed to elicit understanding regarding feasibility and acceptability. Participant interviews took place no more than one month following participants' final COB-MS contact. Notably, ethical considerations were given to the potential power differential in asking extant participants to report on the quality of an intervention that was provided and designed by members of the research team. With this in mind, the embedded patient researcher [21], who was not involved in the facilitation of COB-MS interventions, and who has a diagnosis of MS, facilitated the interviews. Given that the embedded patient researcher was novice in the area of data collection, the audio files for interviews were reviewed by the principal investigator (PI) after each interview to ensure trustworthiness of the interview process.

INSERT TABLE 1 AROUND HERE

2.4 Data Analysis

A content analysis approach was used in the current acceptability study. This approach was taken given (1) the purpose of eliciting feedback on specific concepts deemed necessary to

investigate the acceptability of the COB-MS intervention; and (2) because it facilitates category frequency within the analysis of the interview transcripts with respect to summarising, explicating and structuring the data [32]. This facilitated more concrete indications of COB-MS's potential acceptability, coupled with the richness of exploratory evaluation of data associated with the qualitative tradition. As part of the two separate deductive, content analyses of people with MS and facilitator interviews (led by CPD), data were analysed on a thematic level, coded (and re-coded) according to eight a priori content frames regarding particular phenomena within the COB-MS trial. The content frames used were experience, quality and appropriateness of the program, strengths and weaknesses, changes to the individual, feedback on online setting and recommendations for future administration. A trichotomy of content codes – positive, negative or neutral/unsure/indifferent to particular aspects of the COB-MS program- was elicited from the interview guide. These content codes were used to structure engagement with the data and identification of frames pertinent to each phenomenon of interest (i.e. each interview question) and, cumulatively, the overall acceptability of COB-MS and its trial. To further ensure trustworthiness, codes and frequencies were cross-referenced by the PI (SMH).

Following the content analyses, emergent themes were also extracted, inductively, on a type of post-hoc basis, from the extant people with MS participant interviews [akin to that of thematic analysis; see (33,34)] that reflected recurring concepts that did not conform to content codes, but were nevertheless relevant to the evaluation [35] and potential enhancement of COB-MS. Specifically, Braun and Clarke's [33,34] six-step process was used to analyse the transcripts. Following the transcription, reading and re-reading of each interview, the initial codes were established. Resulting codes were then grouped and re-coded into potential themes, with all relevant extracts collected to cross-reference the potential themes with the original data. Following cross-referencing, themes were agreed among the

research team and appropriately defined. Thematic analyses were conducted with self-reflexivity; that is, through an iterative, recursive process, characterised by the ongoing formation and revision of themes following reading and re-reading of the data [33-34;36]. This analysis process was led by MHO and, to further ensure trustworthiness, reviewed by RAJ, CPD and SMH.

Moreover, trustworthiness was further ensured through member- checking within the OT participant cohort (via three randomly selected participants). As a result of not wanting to place unnecessary burden upon people with MS – living with cognitive difficulties – any additional contact above and beyond activities associated with the trial that required cognitively demanding tasks, such as member-checking review (e.g. given typical delay in time between data collection, transcription, analysis, write-up and circulation), was selected against.

3. Findings

3.1. Content Analysis of People with MS Data

Eleven participants were interviewed from the COB-MS intervention arm (8f, 3m) – this was 22% of the intervention arm of the trial. See Table 2 for participant details. Notably, two of the initial 13 potential interviewees identified declined interview due to MS-related reasons and the next two invitees in the list were contacted. In the case of two participants, there was a delay in the times between invitation, interview organisation and subsequent rescheduling. The duration of such delay was substantial enough where it was deemed inappropriate to invite further interviewees, as COB-MS would potentially be no longer ‘fresh in the mind’, which was a particular concern for this cohort considering their participation in the trial was based on cognitive difficulty.

INSERT TABLE 2 AROUND HERE

Pseudonyms were provided for all participants. Upon analysis of the interview data and patterns in responses, the following four constructs were identified from the eight content frames set out within the interview guide (see *Data Analysis*): Experience; Quality; Appropriateness; and Applied Learning & Improvement (see Appendix 1). Responses that did not conform to these constructs: (1) were collated within a list of recommendations for future program administration (e.g. recommendations for improvement and feedback on the online environment); and (2) remained subject to thematic analysis (see Section 3.2).

INSERT TABLE 3 AROUND HERE

In light of the main findings reported in Table 3, it is worth noting that only two participants held generally neutral to negative views of the program with respect to either what ‘difference it made’ to them (Kevin) or their experience of the program (Harriet). However, it must also be acknowledged that these individuals only attended two sessions and one session, respectively. In Kevin’s case (two sessions attended), he reported:

“In truth, it didn't really make that much of a difference to me... say some of the zoom meetings, I didn't really interact too much with the other people on the course. I wouldn't be particularly outgoing, possibly. Maybe they had more of a conversation with each other, or interaction with each other, as well as that, I think I missed one of those Zoom meetings. Overall, I wouldn't rate it as that beneficial... to me. I wouldn't cast aspersions or say there was anything that was detrimental to it. I just didn't in truth, find it particularly beneficial at any stage. Obviously, I don't know everyone's circumstances, so it all depends.”

According to Harriet, who only attended one session:

“I felt like I was the only one talking. And I kind of said, I'm talking too much. And I thought, No, I can't do this. I was talking too much. [The OT] was asking us all questions but nobody would talk and of course, I talk a lot. It was kind of embarrassing to talk too much and then I said, no I'm not doing this again... and then I stepped down after. Was I just impatient? I felt I was impatient and I felt nobody was talking. And I was talking. I was talking over people then when I'd think of something... then I thought ‘Oh god, I cant be listening to my own voice all the time’. I didn't get anything out of it, I was just, as I say, I didn't give it the time. I couldn't get anything out it. No. Not many were talking. I was talking.”

It can be argued that individuals who did not complete the program (like the other nine interviewees had) or reached some majority threshold should not have been interviewed for an acceptability assessment, as they would not have a complete perspective on the program. However, consistent with best qualitative practice [36], all experiences are valid; and regardless of experience duration, as in this context, it was determined appropriate to include all members of the intervention arm as potential interviewees for this acceptability evaluation. Moreover, despite the short duration of their experience in the program, there remained potential for important insights on the program.

Overall, findings from the content analysis suggest that, from a participant perspective, the COB-MS program provided a positive experience, quality materials and resources and was appropriate for a MS cohort, with a majority of respondents reporting application of learnings following the program, coupled with perceived improvements. Given the recurrence of various concepts that were relevant to the evaluation and potential enhancement of COB-MS, but did not conform to content codes regarding content analysis, a thematic analysis of data from the eleven people with MS interviews was also conducted.

3.2 Thematic Analysis of People with MS Data

Results from the thematic analysis revealed four themes, which represented the varying experiences of the participants within the COB-MS intervention: (1) Group interaction within COB-MS was vital; (2) Online COB-MS had positive and negative effects on participation; (3) COB-MS as a provider of clarity; and (4) Using learned strategies after the completion of COB-MS.

3.2.1 Theme 1: Group interaction within COB-MS was vital

Group interaction and socialisation with other people with MS was identified as important by the participants. As all eight COB-MS sessions were held during the height of the COVID-19 pandemic, including both the one-on-one and group sessions, it was necessary that all sessions were conducted online (i.e. over Zoom), as opposed to in-person. Many participants stated that they would have preferred to have the sessions in-person, as it is easier to communicate, to detect other participant's non-verbal cues and to converse more informally. As Edward stated:

“...so much of communication is non-verbal – we pick up so many signals that... spatially... the way people hold themselves. All these subtle hints out there that you [get] by osmosis. You're up all these things you don't even know you're taking it in, but you are. And that's how you build a picture. That's how you build up relationships. And that's how you build up everything, isn't it?”

Many participants also mentioned that it was informative and helpful to listen to other participants' experiences with the cognitive effects of MS and what strategies have been working or not working for them through group interaction.

“Other things I've done on my own; and I've read them; and I've gone ‘Oh, yeah, yeah, I must do that. Yeah, yeah’. Whereas this was more interactive, even though I've been saying I would prefer it to be in person... it still was interactive, and you did get a bit of a boost when somebody else would pop up with, ‘oh, yeah, that happens to me as well’; or you hear somebody else saying, sometimes that happens to me, so you don't feel so alone with it.” – Cora

While some people found the social-dynamic and rapport-building aspects to be an important part of their COB-MS experience, others found that being in a group created an atmosphere of accountability. In some cases, the group was able to identify supports for different needs of its members. For example, according to Daniella:

“Not everybody had the same goals. So different weeks suited different people more; and then, if there were people having problems (like myself with the memory), one of the girls gave me a tip. So, you know, you're able to help each other out with your tips. Well, what happens? What helps me do something? This is what I do or, so, she was helping me with the memory”.

Group interactions also aided participants in understanding the more difficult or academic points in COB-MS, as some participants found sections of the booklet to be “wordy” and when

participants didn't understand something, they could ask their OT, or understanding would develop out of the context of the ensuing discussion.

“If I was left to kind of just read the book myself, I probably wouldn't have picked up as many tips, I probably wouldn't have processed the book, I suppose... broken it down, or I probably – not that I wouldn't have understood it – but with the OT, and with the other people in my group, we were able to kind of break it all down... give each other tips. I suppose with the OT going through it, I was like, 'alright, okay', I was able to understand the book more.” – Daniella

There were some participants who did not find it easy to engage well with the group and, as a result, did not benefit from COB-MS and only attended minimal sessions, for example, Harriet and Kevin, who were previously addressed in the content analysis.

3.2.2 Theme 2: Online COB-MS had positive and negative effects on participation

Though many of the participants interviewed stated their preference would have been to engage the COB-MS intervention in person, a majority saw the value of the online administration and identified several benefits. Perhaps the most obvious benefit was that using Zoom allowed people with MS to participate in COB-MS during the height of the COVID-19 pandemic.

“COVID [had] the whole country in a heap, so at least it got to go ahead, you know, and that was good. Okay, well, while it wasn't a face-to-face sessions, at least there was sessions, you know?” – Brian

Using Zoom also allowed for COB-MS attendance without commuting. An in-person COB-MS intervention would have made attendance impossible for people who are not able to travel or lived in farther away from the site of the intervention.

“The fact that it was on Zoom, and people didn't have to travel – personally travelling wouldn't have bothered me, but I mean, it's not possible for everybody to travel; but it was grand, you could do it from the comfort of your own home.” – Georgia

Likewise, the online version of COB-MS was also more accessible to people with MS experiencing fatigue and would be less likely able of commuting to an in-person session. As Francine stated:

“I found the programme itself, invaluable; and the Zoom format probably suited me at the time, in that I was suffering very badly from chronic fatigue and not having to travel up and down to a specific place given that I live in, in a rural setting, as most people... I suppose, in Ireland... aren't in urban areas. I know it was as a result of COVID, but the Zoom format actually suited me down to the ground, and I am a chatter, so I did miss the interaction. So, there's a double-edged sword on that one, but the fact that I didn't have to travel with chronic fatigue meant an awful lot to me at the time.”

It is important to note that, though many participants would have preferred face-to-face sessions, overall, the delivery of COB-MS was unaffected by the switch to online delivery, despite it being many participants' first time using the application. As Irma stated, *“I think it's totally adaptable to online”*. However, this ability to adapt may have been device-specific. For instance, Kevin mentioned that he was using a phone to log into the Zoom meetings instead of a laptop or desktop computer, which he reported had limited visuals. Notably, this may also have impacted Kevin's overall experience of the program, as previously addressed.

3.2.3 Theme 3: COB-MS as a provider of clarity

For some participants, the effects of MS on cognition had never been explained to them until their participation in the COB-MS trial. The intervention helped them to understand the cognitive effects of MS through a reliable source.

“When I got diagnosed.... they didn't really let me know what it even was. I'm terrified of Google. I've never... just in case, because Google can be horrible as well. So, I never really Googled it. Now, I know what it is. But it was nice to get the little details... where [they] explained about myelin and all that. When you explain it, it wasn't too...confusing. It wasn't confusing to understand. I loved that that made it a lot more clear.” – Amy

Jacqueline also believed that COB-MS provided clarity on her cognitive symptoms *“... it brought attention to things I noticed a little when I feel that, after doing the course, I'm aware of more things that I wasn't aware of.”* The intervention also provided clarity on how to adapt to cognitive difficulties by using strategies that fit their unique challenges. For example, Francine stated that the intervention made it clear to her that, perhaps some of her cognitive

difficulty might result from being fatigued; and that the strategies included in COB-MS aimed at helping with fatigue were life changing. With that, both Edward and Kevin suggested that though they found it helpful to find clarity regarding their cognition, some people may not be prepared to learn this about themselves. For example:

“Is it possible to prepare... to tell somebody, ‘Hey, you mightn't come out of this feeling great’, you know? So that would be a kind of a self-defeating thing that would mean that they won't do it. So, it actually that's actually a hard one to prepare somebody for”. - Edward

COB-MS also clarified strategies that could help participants with their cognitive difficulties. To some participants, the strategies offered were completely new. As Daniella reported, *“When all the different little tips that I was doing, they were like, ‘oh my god, I'll do that. [...] why haven't I thought of this before?’”* However, many participants were already aware of most of the strategies, but were not necessarily using them at home. COB-MS encouraged these participants to utilize those strategies, making the intervention valuable.

Though many participants commended the program for its clarity, there were sections of the manual were described as “too wordy” and that it could have been helped by additional visually stimulating material, like pictures, cartoons and diagrams. For example:

“You're trying to sort of read it, but it's just all black and white. You can read it, but you sort of, for information to process you have to understand it and I can read and read and read and certain words, but it just kind of don't go in and make sense in your brain. So therefore, how can you ever put that into play? And like, reading things... I've never had an issue... the group activities, all that there, that's good. You have that bit of blue in there. It's all boxed off. It's inviting to look at. It's easy to know.” – Irma

With that, many participants had no problem comprehending its contents:

“The book was really big. Now, I have problems with concentration and reading...I didn't find [it] too bad in that sense, as in each of the chapters were very concise...It was good like that.” – Brian

Moreover, many participants commented that the intervention was easy to understand, because it was facilitated by the OT delivering it in a clear manner:

“She was very clear... She seemed very understanding... like she was easy-going... and straight to the point. She wasn't hard to follow or understand; and she included everybody. ” – Georgia

3.2.4 Theme 4: Participants used learned strategies after COB-MS

Several participants commented on how they used strategies that they had learned or practiced during their time in COB-MS after the intervention was completed, positively suggesting that COB-MS is a potentially sustainable intervention. Participants stated that the strategies were useful and meaningful, particularly with regards to setting up reminders and writing things down as a memory strategy.

“Yeah, if I remember, I'll write it down; and to use stuff I learned and then if I use my phone more, if I have appointments and stuff like that... setting the alarms and let them ring back – things like that. That's handy, tricks like that. They're good tricks to have and I learned all that on the course.” – Edward

The section on fatigue was also reported as helpful for encouraging participants to ‘listen to their bodies’ and practice their fatigue management.

“So, I have stopped fighting the fatigue, I have stopped fighting my body. So, when I feel the need to sit, I sit. I don't... keep going when I know that I need to rest. I take the rest and I pre-empt things; so, I'm not just trying to plough through anymore.” – Francine

In cases where participants already knew the strategies to help their cognition, COB-MS provided the motivation to practice them.

“It gives me kind of the get up and go to actually get up and do it. But maybe it was more laziness on my behalf. Again, as I said it was easy, just to say, ‘ah no I'm too tired’. But then I'd say ‘oh gosh, I'm gonna have to say it now next week if I've done it or I didn't do it’; so, I'm gonna have to do it. But then when I was doing it, I surprised myself. I was happy.” – Georgia

In the cases of both Amy and Georgia, improvements made through using the strategies has helped to improve their moods and relationships with their families. For example, in Amy’s case:

“Oh yes, my mom worries so much, but she could see a difference in me since then, which she's not ringing me 24/7 and she still rings me but... not as much,

as she can see that... she's more relaxed about it and not getting annoyed that... I'm not getting annoyed for her because she's more relaxed with me."

Overall, findings from the thematic analysis suggest that COB-MS has had qualitatively beneficial effects for participants, some of which have lasted beyond the end of the programme. There are also areas for improvement highlighted in the interviews conducted. Notably, all people with MS recommendations for improvement are presented in Table 4.

INSERT TABLE 4 AROUND HERE

3.3 Content Analysis of Occupational Therapist Facilitator Data

Eight facilitator interviews were conducted (8f, 0m)¹. An identifier code was provided for all participants. Upon analysis of the interview data and patterns in responses, two constructs were identified: Feasibility and Appropriateness. Overall, the content analysis indicated that the OTs who delivered COB-MS found the program and its procedure to be acceptable with respect to feasibility and appropriateness (see Table 5).

INSERT TABLE 5 AROUND HERE

Despite all OTs agreeing on the feasibility and appropriateness of the program, they did address one important concern pertaining to each. With respect to the former, approximately half of the OTs addressed concerns over the feasibility of the primary outcome variable – goal-setting, in that they weren't entirely sure that participants understood the concept of goal-setting or if they were truly engaging attempts to achieve goals. For example, it was reported that:

"I don't know if it's reflected in their feedback on achieving the goals or using it towards the goals, 'cause I found they didn't. Even when I kind of fed back to them... they weren't really connecting with them. It was almost like they had just said something for the... purpose – when the assessor came, so I don't know. I just found they got much more benefit from the discussions around some of the things they would have brought up, which weren't necessarily what they had identified in their goal session... nobody remembers what they had said... I think people really benefited from [the program] and I don't know that it will reflect whether they targeted their goals or not." – OT-D

¹ This sample is representative of occupational therapists in Ireland.

In light of this concerns, though, the OTs discussed possible explanations as well as solutions. For example, it was reported:

“I think there would be a bit more of ownership of [goals] if you were meeting face-to-face – a bit like if I had a physio appointment tomorrow, I'd be mad doing my exercises today... I do think there was a little bit of vagueness if people, were feeding back they were like, ‘Oh yeah, yeah, I did do that’ but we have no way of proving whether they actually achieved their goals or not, so it's very much based on... what they're presenting is what's actually happening... I do think there's definitely a bit more ownership of goals, if you're meeting somebody face-to-face and you have to actually present a physical piece of paper to say, well, I tried that 4 times and it worked twice, you know? Because they were very vague.” – OT-G

With respect to appropriateness, whereas eligibility screening for the trial included a minimum threshold for ‘cognitive difficulties’ to participate, there was no maximum threshold, per se – regardless of eligibility criteria including that participants must not be cognitively impaired to the extent where they cannot reliably participate or provide informed consent. Thus, some OTs were concerned over the appropriateness of COB-MS for those with more ‘moderate’ cognitive difficulties. For example:

“I had one gentleman who I would probably... I didn't see his assessments, but I'm presuming that he was probably more in the moderate range of cognitive deficits and I did feel while he enjoyed... participating... I don't know whether he was able to take anything on board... because you're only meeting for one hour per week and maybe something with somebody like that... maybe, if you're doing it one day after the other and reinforcing it; but, one hour per week or an hour and a half per week wasn't going to do it for him.” – OT-I

Overall, OTs found the COB-MS program to be acceptable with respect to both feasibility and appropriateness. They made a number of recommendations for minor amendments to the program’s methodology (e.g. maintaining group sizes between five and seven participants; ensuring early delivery of program manuals to OTs and participants for orientation prior to program commencement; and suggestions regarding session scheduling). With respect to the major concerns regarding the goal-setting outcome variable and higher

levels of cognitive difficulties, though OTs indicated that such concerns did not greatly impact their ability to administrate the program, there is the potential that they could in future iterations of COB-MS delivery. Thus, amendments to the intervention for a definitive trial will be made to overcome these potential barriers to acceptability, feasibility and appropriateness; for example, generation of a new eligibility criterion for maximum cognitive difficulty threshold; greater clarification on goal-setting for OTs *and* participants; and re-evaluation of goal-setting as the primary outcome variable.

4.0 Discussion

The group sessions for the COB-MS provided participants opportunities to meet and discuss experiences with other people with MS who have cognitive difficulties. Though many people with MS will have varying degrees of cognitive difficulty – and in different areas (e.g. attention, information processing, memory, problem-solving, etc.), participants reported that it was helpful to discuss strategies that they use. Hearing similar and relatable experiences of other participants was reported as encouraging for participants. This finding is similar to reports from other studies [17,22,41] which reported that people with MS often felt less alone in their cognitive difficulties due to the group component of cognitive interventions and that it complements use of the strategies (which may be novel to many of the participants), through facilitating working through them together. Notably, there were some participants who did not benefit from the group interaction, who may have dropped out of the programme as a result. This highlights not only the importance of group interaction for the intervention to be beneficial to participants, but also the need for effective group facilitation from the OT. The data also shows the importance of a person-centred approach when providing rehabilitation in MS. The individual needs and preferences of the person with MS need to be considered in light of the intervention being offered.

Pertinent to the impact of social interaction in the current study, as well as a point worth considering for the general interpretation and implications of these findings is the online delivery of COB-MS. Online platforms such as Zoom have become more frequently used to facilitate telehealth services as a result ‘lockdowns’ associated with COVID-19 [37]. As a result, more has been learned about the usefulness, benefits and downsides of using online services, as well as how research can adapt to accommodate these. For example, recent research has: validated remote, online administration of cognitive assessment, such as SDMT, CVLT-II [38], BICAMS and Trail-making Test [39] as reliable as in-person assessment; and suggested efficacy of other online programmes with respect to MS-related fatigue [40]. Similarly, though not the original protocol for COB-MS, amendment from its original design [29,30] to an online platform yielded a number of benefits other than simply being able to administer the programme. Facilitating COB-MS online made the intervention more accessible to participants experiencing fatigue, as it eliminated effort associated with commuting, as well as other impracticalities (e.g. time, resources and commuting). Despite drawbacks associated with engaging COB-MS online [e.g. depending on device used, limited ability to interact socially (as indicated by participants); as well potentially acting as an additional barrier to individuals with cognitive difficulties (37)], online administration was generally well-received by participants and can be argued as viable alternative to in vivo intervention, as it has the potential to offer wider accessibility to participants.

Many participants stated that COB-MS provided clarity on their diagnosis, their symptoms and the strategies they could use to compensate for their cognitive difficulties – which is consistent with results of previous research, for example, by das Nair and Lincoln [17], Klein et al. [22] and Shevil and Finlayson [41]. However, it was stressed by some participants that because people with MS may in some contexts find it difficult to concentrate, retain information or to stay attentive, it may be beneficial to ensure some elements of the

intervention are simplified, such as the manual or the group sessions – echoing participants in research by Shevil and Finlayson [41], who stated that the intervention was at times too complex. As participants in the current study suggested, the manual could contain less text per page and include more visual representations (e.g. cartoons and diagrams), in order to simplify information processing. This is an important consideration in light of OT recommendations regarding goal-setting and the level of cognitive difficulty faced by some participants.

4.1. Limitations and Implications for Future Research

Though the current study yielded a number of interesting findings, it must be acknowledged that, despite achieving a full sample of eight OT facilitators (38% of OT who took part), it did not achieve the sample saturation of participants required to achieve 25% of the population who took part in COB-MS. Nevertheless, the 11 interviews that were conducted yielded full, rich data, facilitated through utilisation of the embedded patient researcher, who was able to build rapport with participants in light of their common MS diagnosis and create an interview environment of authentic openness and sincerity. As a result, these findings are reported with confidence – not only with respect to claims of acceptability, but also their implications.

The findings suggest, despite beneficial reports, some minor amendments are necessary prior to future administration of COB-MS, such as in a definitive trial. These include slight reformatting of the manual², development and provision of reminder text messages, as well as added opportunities to interact socially (e.g. before and/or after each session in a context that can be monitored). Another small, though important amendment to consider is the manner in which goal-setting is introduced and assessed. Goals were set prior

² NB: the manual had been previously been cross-checked in an iterative process by both researchers and multiple members of the PPI panel [see 21)].

to meeting the OT as goal-setting was an outcome variable measured during baseline assessment – by a member of the research team who, for blinding purposes, had no contact with the OTs. Though results and notes from these assessments were forwarded on to the OTs, the procedure for how this is accomplished requires further consideration. It may be the case that something was ‘lost in translation’ somewhere between the researcher and OT, the concept of goal-setting was not made sufficiently clear in its initial introduction through baseline assessment on Goal Attainment Scaling [42] – despite having the opportunity to discuss goal-setting for the entirety of Session 1’s one-on-one OT-participant meeting; or it may have been an artefact of the OTs’ other major concern. That being, some participants’ cognitive difficulty reaching a threshold wherein they had subsequent difficulty engaging the course. That is, some participants may not have understood the link between goal-setting and cognitive difficulty because of said difficulty.

Despite being an eligibility criterion to not have cognitive difficulty to the extent that it compromises reliable participation, there was no objective measure of this criterion other than taking the participant’s word. Of course, such a participant may not be aware of their level of cognitive difficulty and, other than recording scores on a brief cognitive screening test (which did not include a ceiling score), it would not be appropriate for a researcher conducting the screen to make such a judgment based on the limited time speaking with the individual on the phone. It is also quite possible that such cognitive decline could take place over the course of the intervention.

In both cases, minor – though important – amendments are needed. First, the manner in which goal-setting is introduced and described in relation to cognitive difficulties, MS and the aims of the programme requires further consideration and amendment; for example, the strengthening of the explanation for goal setting’s purpose – ensuring clear, concise and accessible transfer of knowledge – from the outset of baseline assessment. Second, it is

recommended that a threshold be determined for high cognitive difficulty and to use that threshold as part of future iterations' eligibility/ineligibility criteria. As recommended by OT participants, it could be the case that those high in cognitive difficulty could be matched and place in the same group – thus facilitating a sub-analysis for inter-group comparison.

However, this may not be feasible for the reasons described above, as well as the rationale for the initial exclusion criterion.

4.2 Conclusions

COB-MS was found to be an acceptable intervention by participating people with MS and the facilitating OTs. The programme was appropriate, feasible and provided both a positive experience and quality resources. Participants reported qualitative improvement and utilisation of their learning beyond completion of the intervention. Both participants and facilitators provided recommendations on how the programme can be refined and improved to facilitate further impact in future delivery of COB-MS. Overall, the findings from this qualitative evaluation of COB-MS recommend it as an acceptable intervention, consistent with its aims; will further facilitate interpretation of results from the quantitative evaluation of trial feasibility; and will provide important considerations for progression to full, definitive trial, as well as future cognitive rehabilitation/remediation and daily functioning studies for people with MS.

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Conflicts of Interest

The authors have no conflicts of interest to report.

Data Availability

The data that support the findings of this study are openly available in Irish Qualitative Data Archive at: <https://repository.dri.ie/catalog/z6044q59n>, “*A Cognitive Occupation Based programme for People with Multiple Sclerosis qualitative feasibility data*” at doi: 10.7486/DRI.z6044q59n.

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Tables

Table 1: Interview Guides

<p><u>Participants with MS Interview Guide</u></p> <ol style="list-style-type: none">1. Can you describe your experience of the programme?2. What did you think of the quality of the cognitive occupation-based programme for people with MS (COB-MS)?3. Did you think the programme was appropriate for people with MS? <i>Prompt (if necessary):</i> Would it be helpful for others?4. What do you think <u>was good</u> about the way in which this programme was run? <i>Prompt (if necessary):</i> Do you think the information and materials were presented well?5. What do you think <u>wasn't good</u> about the way in which this programme was run? <i>Prompt (if necessary):</i> What would you suggest needs to be changed?6. Do you think you improved in any way or that anything has changed since taking part in the intervention? <i>Prompt A (if necessary):</i> How do you see yourself applying what you have learned or experienced from this programme in the future? <i>Prompt B (if necessary):</i> Can you tell us something about the ways in which you have applied your learning or understanding from the programme to things you do in your own life?7. If you were to suggest ways we could improve our programme for the purpose of delivering it again, what suggestions would you make?8. What did you think of the programme being run online? <i>Prompt (if necessary):</i> How do you think that would compare with it being run in a face-to-face, in-person setting.9. Is there anything else you would like to tell us? <i>Prompt A (if necessary):</i> Any other feedback on this potential service? <i>Prompt B (if necessary):</i> Is there anything you feel that we have missed from our discussion today? <p><u>Occupational Therapist Facilitator Interview Guide</u></p> <ol style="list-style-type: none">1. Going back to where we started in this research, can you please describe your experience of the training process? <i>Prompt A (if necessary):</i> What were things you liked about the training? <i>Prompt B (if necessary):</i> What were things you disliked about the training?2. What did you think of the quality of the cognitive occupation-based programme for people living with MS? For example, what did you think of the handbook and other materials provided?3. What did you think of your ability to administrate the programme? <i>Prompt A (if necessary):</i> What were barriers encountered with respect to programme administration? <i>Prompt B (if necessary):</i> What facilitated programme administration?4. Did you think the programme was appropriate for a MS population? <i>Prompt (if necessary):</i> Based on your experience of the programme, do you think it will work to improve cognitive and daily functioning?5. Can you describe your overall experience with the programme?

Prompt (if necessary): Though you are not allowed to share this programme with others at this time, would it be something you would recommend to colleagues, for example, in terms of recommending training if it were made available?

6. In your own experience, if you were to suggest ways we could improve our programme for the purpose of delivering it again, what suggestions would you make?
7. For future iterations of programs like this, how do you think clinicians, like occupational therapists, be educated to optimise recruitment to take part as you did?
8. What was your experience like in running this program online and do you think administrating COB-MS in a traditional, face-to-face setting would have worked better?

Prompt A (if necessary): What worked well in the online setting?

Prompt B (if necessary): What didn't work well or needs to be changed for the online setting (e.g. technical difficulties)?

Table 2: COB-MS Participant Details

Pseudonym	Gender	Location	Work status	MS type
Kevin	M	Town	Long-term disability benefit	Relapsing remitting
Harriet	F	Town	Carer	Unknown
Edward	M	Countryside	Farmer	Secondary progressive
Cora	F	Town	Retired teacher	Unknown
Daniella	F	Countryside	Stay at home parent	Relapsing remitting
Brian	M	Countryside	Long-term disability benefit	Relapsing remitting
Georgia	F	Countryside	Cleaner	Relapsing remitting
Francine	F	Countryside	Teacher	Secondary progressive
Irma	F	Countryside	Stay at home parent	Relapsing remitting
Amy	F	Town	Nurse	Relapsing remitting
Jacqueline	F	Town	Long-term disability benefit	Secondary progressive

Table 3: Content analysis of Participants with MS responses

Construct	Example Quote(s)	Code	Frequency
1. Experience	<p>I loved it, if I'm honest. It was nice to interact with other people that have this... it was nice to hear other people's experiences... and I loved the tips, getting the whole way through with the help; it was brilliant, I did I really enjoyed, I really took it on. - Amy</p> <p>“It was good. I enjoyed it... definitely a positive experience.” – Cora</p> <p>“It has been absolutely invaluable. So, my experience has been life altering.” – Francine</p> <p>“I personally enjoyed it and have to say I looked forward to it every week and it was nice you know, seeing people face-to-face [online] and talking about similar topics.” – Georgia</p> <p>“I thought it was very worthwhile; and I've taken stuff from it, and applying it to my every day.” - Irma</p>	Positive	<p>82%</p> <p>(9/11 + 1/11 Neutral 1/11 -)</p>
2. Quality	<p>“Yeah, I thought it was very good. I suppose the Zoom meetings were very good. The therapist that was holding them knew her stuff. She was very good. Yeah, she was very good. No, I had absolutely no problems at all.” - Brian</p> <p>“Oh, I thought it was great. As in I think even people that don't have MS, and have problems with their memory could do with the book.” - Daniella</p> <p>“Oh yeah, fine everywhere. Everyone in it was very good, there was no issue with any of that... There was no issue with their delivery or any of that.” – Edward</p> <p>I suppose, I have no problem [with the quality]... Having the book was good, for all the information, that you could go back on it when you finish the talking and all that... sometimes you forget about everything, you know, so the book was a great idea in that sense. The fact of zoom was a good idea because it's supposed to reach out to people that can't travel and stuff... it was a good idea that was only a small group. – Jacqueline</p>	Positive	<p>82%</p> <p>(9/11 + 2/11 Neutral)</p>

3. Appropriateness	<p>“Oh definitely, I do definitely (think the programme is appropriate for people with MS)... It makes me feel better for - this is not my fault, what's going on and I have to just go on with it... But yeah, I do think that it would help people, a lot.” – Amy</p> <p>“It's totally suitable for people with MS, but also other people... Like...one of the girls, I was like, ‘Oh, I'm actually taking part in in a research programme and I have these tips for you’.” – Daniella</p> <p>“Go with it, trust it. It just it may seem strange, it may seem like how is this going to help me? How can somebody make my brain work that bit better and thinking and do and in remembering? It does work and you need to be open, open to follow it, in order for it to help you.” – Irma</p> <p>“I've done a lot of stuff with MS over the years you know so this has been a good eye opener... knowledge is power really – it’s good to know, to stop and think about things. You know, you would be dreading things, like but if you sit down and say yeah, it's doable like.” – Jaqueline</p> <p>“The questions were quite relevant to my situation at least, and the test could be a bit challenging, or point out to any particular difficulty you had with your memory.” - Kevin</p>	Positive	82% (9/11 + 2/11 Neutral)
4. Applied Learning & Improvement	<p>“It's brought all of that back into my head. It's made me more aware of strategies to use, things to do not to just get overwhelmed. And just to take it easy, take it slowly, it takes as long as it takes, but you'll get there. So, it has definitely helped me. Yeah it has.” – Cora</p> <p>“The main thing I learned to do is I have to record everything I need to do somewhere, be it in my phone or be it on a piece of paper or something like that and leave a piece of paper on the on the table at night-time; because I will forget.” - Brian</p> <p>“I'm not as tired because I'm not trying to do everything all at once, I've split it out. So, I read a book on my phone, okay.. and I was writing on post-its, and I was rereading the post-its to remember where I was. I couldn't remember where I was. At the minute, I know where I am. I don't need Post-its, I know where I am when I pick up my book. Unbelievable. I remember where I am and what's happening.” – Daniella</p>	Positive	64% (7/11 + 2/11 Neutral 2/11 -)

“Yeah, bits and pieces I just write. Yeah, if I remember, I'll write it down. And to use stuff I learned and then try to use, you know, if I use my phone more if I have appointments and stuff like that, it's just, setting the alarms and let them ring back, and things like that. That's handy. They're good tricks to have and I learned all that on the course.” - Edward

“But even with the bits I am doing, I've seen a significant improvement in terms of my quality of life... I'm not dragging myself through the days and I'd have huge improvements all sides and it all stems back from doing the COB-MS programme and everything I learned from that. So, as I said, it was it really has been life altering in terms of just giving me the tools and giving me the information I needed to go forward.” – Francine

“I can say that I did get some benefits out of it, as in like setting goals for myself. It was easy just to sit back and just get on with your every day, you know, living... I'm in better form and everybody else seems to be in better form – now... I'm not in brilliant form 24/7; but, I'm not as narky, you could say, cuz I'm not just as tired.” – Georgia

“I feel before I used to be rushing to get things done, but then when I did the [COB-MS]... if I was still kind of in a hurry to do a thing... if I slowed down, I'd do it better. I changed some a few things in the last few months that I kind of wrote off to be honest. I wanted a bit of a garden and I just wanted a few flowers and stuff and I've achieved that as well, which wasn't on my list of things to do but it just happened for me, because I suppose I was thinking differently. Now I have a little garden to look after.” - Jacqueline

Table 4

Table 4: Participants with MS recommended amendment for future administration of COB-MS

- Increased interaction with others (aside from the program per se, e.g. before and/or after sessions)
 - The amount of words in the manual, per page could be decreased; likewise, an audio-based version of the manual was recommended.
 - Participants could be sent a weekly reminder text (e.g. what was covered in the last session, home activities to be completed for next week, etc.)
 - Inclusion of a psychotherapy-based module/session
 - Being made aware of baseline scores or an index of scores in advance, for personal tracking of change.
-

Table 5

Table 5: Content analysis of occupational therapist responses

Construct	Example Quote(s)	Content Code	Frequency
1. Feasibility	<p><i>“...on a feasibility level, I would feel that it was a ‘runner’, just going on my own experience and of the group that I facilitated. I had varying levels of ability, but all very workable.” – OT-H</i></p> <p><i>“[Participants] said that the course was really beneficial and that in the future, that it would definitely be something that they would implement, kind of long-term, that it was great that they had the handbook to kind of look back on... So, that was really beneficial to them.” – OT-A</i></p> <p><i>“...with some of the participants I had, I didn't think that it would do that well and, actually, they implemented them and came back and fed-back that they actually found that great; and you know... if you're working on that and engage in all of these things, it's obviously going to improve your cognition, your ability to remember your attention, all of that. So, I thought, in conclusion, that was really good.” – OT-B</i></p>	Positive	100%
2. Appropriateness	<p><i>“To be honest, I was actually, I'm not sure ‘surprised’ is the right word, but I suppose just pleased at how I was able to facilitate it; and because I don't know why I kind of thought that the course is just something in isolation, but obviously it's very clear now that you're using all your OT skills and you really fall back on them and all your experience to date and anything that comes up... even if it's not really pure cognition or management of fatigue or any MS topic... I found that I was giving advice on things that I would do generally in work. So, I just found that I think it just really suited the OT profession very well, because I felt like I had the skills to deal with whatever came up and... I think it went really quite well and... they had mentioned that it was kind of easy to pick up on it and that's obviously due to the program and the handbook as well...so, there didn't seem to be any issues really at all.” – OT-B</i></p> <p><i>“That’s what I like about it – that it’s sooo OT-focused...what was lovely about this is that it really highlighted OT and I know it was based on PEOP and I thought that was lovely the way you’re</i></p>	Positive	100%

	<p><i>bringing in all those aspects around cognition and how they can affect and how they can be used to help the person and so I'd like to keep it – I'd like to keep it as if it were mine! [laughs] But to keep it OT, because I just think... people really benefited from it.” – OT-D</i></p> <p><i>“It was great... I think everybody who was in my group really loved it, they were very happy with the content... Everyone really loved the cognitive fatigue. I think [PI] even said that in the training, was to spend a lot of time on this because it's a huge piece. So, I found the content very appropriate and I liked that... I kind of kept coming back to the same ideas, so that it really came across to the participants week after week, and just reminding them of what we did before and how you can implement it in this scenario and in this scenario.... So I felt that it went very well and the content was right on.” – OT-E</i></p>		
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