

A cognitive occupation-based programme for people with multiple sclerosis: A new occupational therapy cognitive rehabilitation intervention

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Abstract

Introduction: Cognitive difficulties have been reported to have the greatest effect on function and quality of life in people with multiple sclerosis, affecting 50–60% of people. To date, few interventions have been developed to treat cognitive issues in multiple sclerosis. Here we report on a Cognitive Occupation-Based programme (COB-MS) for people with Multiple Sclerosis an evidence-based intervention to address everyday problems encountered due to cognitive difficulties. The aim of this research was to explore the views of people with multiple sclerosis and occupational therapists on the programme and its potential implementation in practice.

Methods: Data were elicited from a purposive sample of 12 people from two stakeholder groups, people with multiple sclerosis ($n = 5$) and occupational therapists ($n = 7$), through focus groups and interviews. The programme and related materials were presented, and contributions recorded, transcribed and thematically analysed.

Results: Two main themes were identified from analysis of the data: response to the intervention and challenges to implementing the programme. Occupational therapists agreed that the COB-MS is client-centred. People with multiple sclerosis thought that it was a validating intervention. The overall format was viewed to be useful and feasible.

Conclusion: The COB-MS for people with Multiple Sclerosis is the first known cognitive intervention using an occupation frame of reference to address difficulties faced among persons with multiple sclerosis and was found to be timely and relevant to the needs of the population.

Keywords

Cognition, occupational therapy, multiple sclerosis, intervention

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Introduction

Rehabilitation with people with multiple sclerosis (MS) comes with unique considerations such as the fluctuating nature of the disease, patient fatigue and emotional and psychological well-being of the individual (Siepman et al., 2008). Difficulties with cognition have been reported to be present in 50–60% of people with MS (Amato, Zipoli, & Portaccio, 2006). ‘Cognitive rehabilitation is a process whereby people [with cognitive difficulties] work together with health professionals to remediate or alleviate cognitive deficits’ (Wilson, 1996, p. 637). To date however, there is a paucity of evidence as few programmes have been developed for people with MS that decrease the detrimental effects of impairment, and support patients by

helping them to function well in everyday life (Rosti-Otajärvi & Hämläinen, 2014).

In two Cochrane systematic reviews, one in memory rehabilitation in MS (das Nair, Martin, & Lincoln, 2016) and one in neuropsychological rehabilitation in MS (Rosti-Otajärvi & Hämläinen, 2014), the authors found either no evidence (number of included

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studies = 8) or low level evidence (Rosti-Otajärvi & Hämäläinen, 2014; number of included studies = 20) that rehabilitation reduces cognitive symptoms in MS. Despite the findings from individual studies being generally positive (in 18 of the 20 studies included), the pooled results of a meta-analysis by Rosti-Otajärvi and Hämäläinen (2014) suggest that the effectiveness of cognitive rehabilitation for people with MS is far from conclusive. The included studies used computerised training, external aids and compensatory strategies, supporting awareness of cognitive deficits through education and awareness or a combination of these. The conclusions of these reviews were based on the limited quality of the research that is available. Both reviews emphasised a need for more robust randomised controlled trials (RCTs) that are of strong methodological quality in the area before any firm conclusions can be made on the possibility of improving functioning through cognitive-directed interventions.

Goverover et al. (2018) updated the review by O'Brien, Chiaravalloti, Goverover and DeLuca (2008) where they noted substantial progress has been made in the area of cognitive rehabilitation in MS since the initial review was published (40 studies included). They conclude that much work has yet to be done to develop the best evidence base for cognitive rehabilitation in MS. Methodological rigour and strong design are essential components to developing the evidence base in the area. Khan and Amatya (2017) carried out a systematic review of systematic reviews in the area of rehabilitation in MS. Though, not specifically looking at cognitive rehabilitation they also found that overall there is a lack of high quality evidence for a range of rehabilitation techniques in MS and that evidence is inconclusive in many areas, including cognitive rehabilitation. The authors found 'low-quality' evidence for occupational therapy interventions for participants with MS (96 trials) and in the area of cognitive rehabilitation (32 RCTs). Here authors again conclude that more rigorous trials are needed.

In contrast, das Nair and Lincoln (2013) found evidence that group-based memory rehabilitation improved insight and acceptance. The findings indicate that there are positive impacts on daily life, mood, fatigue and quality of life of cognitive rehabilitation that are being captured through qualitative means, but not quantitatively.

O'Brien et al. (2008) recommend that research should focus on function and context and aim to generalise to daily life and not be domain-specific. New interventions should aim to increase participation (O'Brien et al., 2008) and have outcomes that measure impact on daily living (O'Brien et al., 2008; Rosti-Otajärvi & Hämäläinen, 2014). Rosti-Otajärvi and Hämäläinen (2014) also recommend that all future

studies should have a clear aim that is determined before beginning and the primary outcome should reflect this. They also suggest detailed reporting of the content of the intervention. Khan and Amatya (2017, p. 365) call for intervention that 'engage, educate and empower patients'. Findings and recommendations from this summarised review of the literature provide strong rationale for the development of the cognitive occupation-based programme for people with multiple sclerosis (COB-MS) given the marked clinical treatment gap.

From the recommendations provided and the evidence that exists to date there is a clear need for a new individualised cognitive intervention that is measured by and taught through occupational participation, meaning that the focus will be on daily life activities such as self-care, productivity and leisure. The focus of the COB-MS is on managing daily life, employment and community engagement using routines, compensatory strategies and streaming demands. The emphasis is on helping people to participate more effectively in the daily occupations that they find difficult due to their cognition. The programme is an adapted version of an intervention that was designed and used as part of a computer-based training programme for older people that included instructional videos (Hynes, 2016). The instructional videos (Hynes, 2016) were transcribed and included in the handbook and the content was then modified for use with people with MS. Many of the successful aspects of previous research with people with MS (e.g. Chiaravalloti, DeLuca, Moore, & Ricker, 2005) and other populations (e.g. people with brain injury; Levine et al., 2000) were incorporated into the intervention. A preliminary version of the COB-MS, including facilitator handbook detailing the intervention and handbook for people with MS, was thus developed. This new programme has yet to be used with chronic conditions.

Following the MRC guidelines for developing and evaluating complex interventions (Craig et al., 2008) the first step is 'Development' which includes identifying the evidence base and appropriate theory and evaluating facilitators and barriers to implementation and acceptability of the intervention. Only following this should feasibility or pilot testing in future trials take place. To support this, we undertook a consultation process with occupational therapists and people with MS to elicit their views on the proposed intervention. In particular, we set out to answer the following research questions:

1. Is the COB-MS an acceptable intervention for people with MS and occupational therapists?

2. What are the facilitators and barriers of the potential implementation in practice of the COB-MS for occupational therapists working with people with MS?

Method

This is a qualitative descriptive study. This design was chosen as it is suitable for obtaining straight and largely unadorned answers to questions of special relevance to health care practitioners (Sandelowski, 2000) including the development and acceptability of a new intervention such as the COB-MS. A generic qualitative approach was taken here as it was not guided by explicit assumptions (Kahlke, 2014).

Participants

Non-probability purposive sample was chosen for this study. Recruitment of people with MS was through the local Multiple Sclerosis Clinic. Posters were hung in the reception area of the MS clinic. The study was also promoted through the local chapters MS Society of Facebook Page. Researchers had no access or involvement in promoting the study through Facebook – this was done by the Community Services Coordinator. Participants contacted researchers if they were interested in taking part. Occupational therapists were recruited through an E-blast that was sent to clinicians working in the area. Clinicians then contacted researchers if they were interested in taking part. Written informed consent was obtained from all participants. Ethical approval for the study was provided by the University of British Columbia Behavioural Research Ethics Board (H15-02333).

Participants with MS were eligible if they were: (1) 19 years or older, (2) fluent in written and spoken English, (3) diagnosed with MS, (4) reported cognitive difficulties (this was not assessed by the researcher unless there was a need to assess capacity), (5) clinically stable, and (6) living in the community. People with MS were excluded if they had cognitive difficulties that would affect reliable participation or capacity to give informed consent. Guidelines from the British Psychological Society (2008) were followed in relation to capacity assessment. There was no need to assess capacity for anyone who self-selected for the study.

Occupational therapists were eligible to participate if they were: (1) working clinically at the time of the study, (2) agreed not to distribute the COB-MS material and return it following interview, and (3) had clinical experience with people with MS or

people with cognitive difficulty of a minimum of one year.

Data collection

Both interviews and focus groups were used to explore participants' views on the COB-MS. Interviews were used with occupational therapists due to difficulties scheduling a focus group with this group. A focus group was used with participants with MS. This type of health care consultation is being used more frequently to develop interventions with people with various health conditions, including people with cognitive difficulties such as dementia (Hynes et al., 2015). Focus groups were chosen as group members build off each other's responses leading to more in-depth answers.

Participants with MS received a hard copy of the COB-MS handbook at least seven days before the focus group took place. They were asked to read the handbook and make any relevant notes prior to the focus group and take these to the group. During the focus group the facilitator followed a topic guide (see Appendix I) to elicit the views of participants on the COB-MS programme. Both authors were present at the focus group, one facilitated the group (SMH) and the other took field notes (SF) and was available to support members if required. The focus group lasted for one hour. Both researchers are occupational therapists and have experience of conducting focus groups. The programme was first explained in detail and discussion around its content and that of the handbook were recorded. Topics covered included impressions of the COB-MS, what they liked/disliked and thought was missing from the programme. Specific questions about the handbook were also covered. The discussion was flexible and led by the participants. Field notes were taken and the session was audio recorded. The group recordings were transcribed and analysed and no identifying names or details were included in the transcription.

Occupational therapists who met the inclusion criteria were provided with the facilitator COB-MS handbook. They were also given detail of the project either by phone or by email and had at least seven days to read the handbook before being contacted for a semi-structured interview. Participants were able to complete the interview by phone if it was not possible to interview in person. The interview followed a semi-structured format, lasting about 30 min, and used a pre-defined topic guide (see Appendix II). Occupational therapists were asked for their views on the feasibility of the programme and the usefulness and relevance of the content of the handbook. Any changes

suggested were noted and interviews were audio recorded and transcribed.

COB-MS programme

The COB-MS programme consists of eight sessions – two individual and six group-based. Session one involves an initial visit with an occupational therapist who explains the programme in more detail and helps the participant set some personal goals. There are then six once-weekly group sessions with a small group (between five and eight people). The group sessions are then be followed by individual sessions that take place two weeks after the last group session.

The focus of the COB-MS is on managing the demands of employment and daily life by using

compensatory strategies, routines and learning new techniques that can be integrated into daily occupations and contexts in order to make it meaningful to the participant. The programme takes a three-pronged approach to cognitive rehabilitation, using education, remediation and adaption to help people meet their goals while managing their cognitive challenges. Cognitive challenges in MS usually consist of deficits in complex attention; slowed processing speed; and problems with information processing, executive functioning and long-term memory (Chiaravalloti & DeLuca, 2008). The programme is informed by The Person–Environment–Occupational Performance model (Christiansen et al., 2011). Table 1 summarises the content of each of the 60 min sessions.

Table 1. COB-MS sessions.

Session	Brief content
Session 1 (individual)	Focus on You <ul style="list-style-type: none"> • Initial meeting with the OT – briefing on what will be involved in the COB-MS • Goal setting with the person with MS on occupations that they wish to target
Session 2 (group)	You and Your Cognition <ul style="list-style-type: none"> • Education about the brain and cognition • Discussion on how MS can impact cognitive function, particularly memory, information processing, attention, problem solving and new learning • Discussion on the impact of cognitive difficulties on day-to-day occupations
Session 3 (group)	You, the Centrepiece <ul style="list-style-type: none"> • How the cognitive difficulties affect you? • What changes can be made by you? • What can we learn that can help? • Discussion and application of strategies
Session 4 (group)	You, The Person <ul style="list-style-type: none"> • Further concepts on what changes can be made by you • Internal strategies to practice and apply • Discussion around sleep and sleep diaries • Further exploration of strategies
Session 5 (group)	Your Environment <ul style="list-style-type: none"> • How does the environment impact cognition? • What can we change that might help • Application of external memory strategies • Managing distraction and the impact of other factors on cognition
Session 6 (group)	Focus on Doing <ul style="list-style-type: none"> • How are our occupations and daily life affected? • What can we do to help integrate strategies into daily life • Examples of how to adapt or remediate occupations
Session 7 (group)	Seeking New Challenges <ul style="list-style-type: none"> • Seek new challenges with strategies that support success • Set goals for yourself • Stay motivated, maintain progress and on-going adaptation • Group conclusion and debrief
Session 8 (individual)	Testing the Application <ul style="list-style-type: none"> • Review goals and strategies used • Plan for future • Discussion around useful groups and services • Debrief and summary

COB-MS: cognitive occupation-based programme for people with multiple sclerosis; MS: multiple sclerosis; OT: Occupational Therapist.

The handbook that was provided to people with MS and occupational therapists was approximately 125 pages in length. It contained detailed information on what is covered in the COB-MS sessions. The exercises, activities and strategies that are covered in the programme are available in the handbook to practice and apply.

Analysis

An inductive approach was taken to data analysis. The audio recordings were transcribed by an individual outside of the research team and the transcripts were then checked for accuracy by the lead author (SMH). The transcripts were not checked by participants because the lead author relocated shortly following the focus group and this was not possible as a result. Analysis of the data, which consisted of audio recordings of focus groups and interviews and field notes, was through an inductive thematic approach (Braun & Clarke, 2006) and carried out by the lead author using the QSR International's NVivo 10 Software (2012). The following steps were followed:

1. Once the transcripts were checked by the researchers to ensure content was correct the transcripts were read (by SMH) several times to ensure emersion in the data.
2. The transcripts were read again (SMH) and this time a list of codes were produced for each one of the transcripts.
3. From this list of codes, themes were generated and discussed with the second author (SF).
4. Both the themes and codes were re-checked and revised, changed or dropped if appropriate, in the context of the full set of transcripts.
5. The themes were then defined by the researcher (SMH), using the codes that were related to each theme.
6. The relevant quotes from the transcripts were then assigned to each theme to ensure that the evidence

for each theme was clearly shown (See Appendix III for example from Theme 1).

7. Transcripts, themes, codes and definitions were checked again with the second author (SF) before analysis was concluded.

Results

Participant demographics

Eight occupational therapists and ten people with MS volunteered for the study. One occupational therapist was excluded because they reported not having enough expertise working with people with MS. Five people with MS were also excluded as they were unable to commit to the requirements of the study – two people were unable to attend the focus group and three people were unable to review the handbook in the timeframe required. As a result, seven occupational therapists and five people with MS participated in the consultation (see Tables 2 and 3). All participants were female.

Only one participant reported having received treatment for cognition – this treatment was reported to have been provided by an occupational therapist. Another participant reported trialling various methods of self-treatment including Lecithin, meditation and massage.

Themes from the data

Two key themes were identified in the data that were evident in discussions with both people with MS and occupational therapists (See Table 4 for themes and sub-themes). These themes were response to the COB-MS intervention and challenges.

Response to the COB-MS intervention. When participants were asked what their first impressions of the COB-MS was all participants responded positively, participants

Table 2. Demographic characteristics of participants with MS.

Code	Age	Marital status	Education	Employment status	Years since diagnosis	Type of MS	Self-appraised difficulty
11	58	Common law/married	College diploma	LTD	20	SP	Moderate–severe
12	52	Single	College diploma	Pension plan for disability	14	SP	Moderate–severe
13	60	Single	College diploma	LTD	23	RR	Mild–moderate
14	57	Common law/married	College diploma	LTD	5	RR	Moderate
15	54	Single	College diploma	LTD	21	RR	Moderate–severe

LTD: long-term disability; MS: multiple sclerosis; RR: relapsing remitting; SP: secondary progressive.

Table 3. Characteristics of occupational therapist participants.

Code	Years working	Frequency working with people with MS	Frequency working with cognition	Current area of practice
21	8	Infrequent	Frequent	Private practice
22	9	Frequent	Frequent	Acute care
23	6	Frequent	Frequent	Home and community care
24	11	Very frequent	Relatively frequent	Inpatient and outpatient rehabilitation
25	14	Very frequent	Very frequent	Community care
26	6	Infrequent	Frequent	Community care
27	9	Infrequent	Frequent	Residential care

MS: multiple sclerosis.

Table 4. Themes and sub-themes from data.

Theme	Sub-themes
Response to the COB-MS Intervention	<ul style="list-style-type: none"> • Positive impressions of the intervention • Good fit between the intervention and the person • Uncertainty about aspects of the intervention • Aspects of layout, formatting – suggestions for improved usability • OT-specific responses to the intervention • Family – understanding that family is also living with cognitive difficulties and need for inclusion in intervention
Challenges	<ul style="list-style-type: none"> • I'm not alone – validation that it is a symptom of MS • Goal setting • OT-specific – challenges implementing the COB-MS in practice • Group practicalities – challenges for the group likely to attend • Best time for COB-MS to maximise its impact

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with MS particularly. Many spoke of the significance of having a handbook and intervention that they feel was a good fit for them and the difficulties they encounter in their daily life.

I couldn't believe it. It described my memory to a T. (PMS15)

It's like a bible, basic instruction, it's like I'm so glad! It's gold, yeah, it's really gold. (PMS11)

For the occupational therapists there was satisfaction with the philosophy of the COB-MS, what it prioritises, how it runs and its inclusiveness, as suggested in the following:

It really was obviously client-centred, giving them the control and all those things I really, really like. . . I really like that it's so occupation-based and occupation-focused. . . I would love to be able to implement this program because it just seems very, very comprehensive and very much you know, having that occupation focus um and client centred focus really resonated with me. (OT27)

I like how it incorporates the holistic view of the person, like it. . . doesn't just isolate cognition. (OT26)

Participants with MS also spoke about how they appreciated that the person was being viewed holistically and that they were shown how to work towards and plan for the future.

'I like how there's a section on seeking new challenges. . . I'm not just gonna exist, I'm gonna live fully and I think I really like that' (PMS11).

All participants with MS stated that they were unaware that MS could cause cognitive difficulties until quite recently.

It was something that had in the past caused them to feel negatively about themselves: 'When you get with people you don't know very well, they just think you're stupid' (PMS14).

One participant said that she had wanted to continue working but felt forced to leave her job because she

was becoming overwhelmed and did not feel capable of dealing with work.

I honestly think that if I had been aware when I was working of a lot of these...I might have been able to lengthen my tenure...not to have to just say 'ok I gotta get out of here, there's no way to deal with this'. (PMS14)

This fear was amplified by the fact that participants were unaware that their problems were as a result of MS and that there might be strategies that they could have used to help. When discovering their difficulties were MS related, all of the participants reported feeling reassured.

'It validates you. Yeah, you stop blaming yourself and the outside yourself says "this isn't you, this isn't what makes you you' (PMS12).

Having that information had a positive impact on this group of participants. They found that it 'was just a relief to say "ok, it's not me, it's the disease"' (PMS14) and that 'it was almost like it gave permission' (PMS11). One of the occupational therapists stated that one of the obvious strengths of the COB-MS is that the group format may offer informal peer support and re-assurance. This could be very valuable to people who have yet to know the commonality of their experience. One participant with MS and one occupational therapist spoke about how the COB-MS could help to inform family members about the difficulties with cognition that they are experiencing. One participant stated that she was able to use the COB-MS handbook to describe her experiences to her sister:

'It was such a great way to say to [my sister] "this is what I've never been able to explain to you"... for me to understand that and see that was just fantastic!' (PMS13).

One occupational therapist suggested including family members in the group sessions, particularly in the first group session. The occupational therapist thought that it would serve two purposes – educating the family member and also making them aware of the importance of committing to the intervention. None of the participants with MS stated that they felt that their family or support network should be included in the group.

Occupational therapists and participants with MS valued that current issues in MS were dealt with in the programme:

'What I really like about it, it brings up the trending stuff now' (PMS11).

The examples that were given were available apps, use of cannabis and mindfulness training. Some sections in particular were singled out by occupational therapists as being particularly useful. They spoke specifically about the exercises, homework and strategies that were taught in the group sessions. They felt that the exercises would be effective and appreciated that they were based on existing evidence. There seemed to be an appreciation among the occupational therapists for the level of evidence that was presented throughout the handbook. They spoke about the benefits for the therapists in terms of getting clients engaged in the programme:

To give details of different research that was done or experiments I think engages people in a different way where they go "oh! This has been shown to work" and it just kind of adds credibility to what you're saying and may be the breaking point of actually getting them to try strategies...I just felt that was a really nice thing to include. (OT27)

One of the occupational therapists questioned whether the COB-MS was too flexible and if it would benefit from 'a more prescriptive format'. She thought this was important factor when the COB-MS was being implemented by less experienced clinicians.

'I think the flexibility within the program leaves it vulnerable to not being as standardized as you might wish for it to be' (OT26).

The occupational therapists were asked if they thought that the COB-MS would require training. Four of the therapists thought that training would not be necessary and three thought it would. Of the three people who thought training would be necessary, two thought it only necessary for newly qualified therapists or people with minimal experience working with people with MS. There was agreement that training should be optional and the most common suggestion was for online training.

Challenges. The area that there was some uncertainty about was goal setting, and this was stated by both stakeholder groups. Participants agreed that it might be difficult to come up with goals so early in the intervention.

'They haven't been given information so it's hard to create goals when you don't have any strategies' (OT22).

There was discussion around this issue during the focus group and some participants were hesitant about setting goals.

‘Setting objectives, that’s something I find very hard to do...I find it intimidating to be told I have to set goals... It’s not that I cannot do it but I probably need a lot of help actually verbalising it’ (PMS14).

Although this was a concern that was identified by both groups not all participants thought that it would be a problem. Two of the occupational therapists specifically identified the goal setting as a positive and thought it was well-placed at the beginning of the intervention. One participant with MS stated how she thought that the goal setting was clear and comprehensive.

‘This is so well illustrated, written, on how to make a goal, it’s just incredible’ (PMS12).

Both groups believed although the intervention would be useful at almost any stage of MS, in order to get the most impact the right time to implement the COB-MS would be relatively soon after diagnosis. All participants with MS agreed with this timing and would have liked to have been offered the COB-MS when they were first diagnosed.

If I had any of this when I was early in my diagnosis and still in the business world, I may have been able to stretch my time in the business world before I finally conceded to it...The material probably would have at least saved two of my jobs. (PMS12)

They felt that providing supports to newly diagnosed people would help, particularly people who are in the workforce hiding their symptoms. There was agreement from the occupational therapists in this regard also. They felt that providing the information to people before they needed it was a sensible preventative measure.

‘If you were doing it in the early MS population, people who are still functioning relatively well...we know from experience that if people learn these strategies before they absolutely require them, carry over’s a lot better’ (OT24).

The occupational therapists also spoke about the challenges that come with running a group if people are experiencing significant cognitive difficulties, including difficulty processing information, people

not having insight into their difficulties and possible motivational problems.

One occupational therapist worked in private practice and stated that for her a group intervention would not be an option. Most of the occupational therapists also stated that they would have two main barriers in running a group in their current practice – getting to sessions and getting the numbers for a group. Many of their clients would not be able to make a weekly group session because they live too far away and driving long distances would be a barrier. For others it would be too difficult for the clients to attend the weekly sessions as they already are having difficulty with their daily activities.

‘What I see is people are trying so hard just to manage their daily activities, like getting themselves dressed, getting their meals cooked, just maintaining their very, very basic ADLs...you’d be hitting a very select population’ (OT23).

Four of the occupational therapists stated that they would struggle to get the numbers to run a group like this. Having people in a group who have similar levels of cognitive function may also prove challenging according to two of the occupational therapists interviewed. That said there were also benefits seen to running the COB-MS as a group as stated by one occupational therapist in the context of working resourcefully.

‘Having the group format is a selling point because it’s such a great use of the therapist’s resources’ (OT27).

Another occupational therapist said that they would like to see the COB-MS available in an individual format.

The occupational therapists also stated that having the time available to them to run the group would be an important factor. With large caseloads and urgent and palliative clients for some of the occupational therapists they could not guarantee that they would be able to prioritise running a weekly group unless they had someone to cover for them. Having support from managers was noted by one of the occupational therapists as being

‘The most significant consideration’ in deciding whether to implement the COB-MS. The occupational therapists were, however, positive about the future of the COB-MS. ‘I think it would work really well actually...I loved it! I wanna keep it, I don’t want to give it back to you!’ (OT25).

Discussion

Here we found that people with MS and occupational therapists welcomed the development of the COB-MS and were positive about its usefulness and implementation. Some challenges exist when implementing a group-based programme such as the COB-MS with a population that has a chronic condition but the programme was well received with little divergence of opinion evident from the data.

Participants in both groups expressed their appreciation for having available an intervention that is such a fit to their own experiences. Similar to das Nair and Lincoln (2013) participants spoke about the control that an intervention like this would have given them over their condition, particularly in the early stages of the condition. Participants with MS were not newly diagnosed but they suggested that the group would be best suited to a newly diagnosed group format. This would also lessen some of the challenges that were identified by the occupational therapists in relation to running a group with a more severely affected population. Based on the feedback from participants some changes will be made to the COB-MS programme such as the inclusion of information on a number of online resources and some grammatical and language changes in places for people with MS. For occupational therapists, the updated COB-MS will include more information on goal setting and guidance on follow-up, as well as tips on running groups and suggested outcome measures for use by occupational therapists. The length and structure will stay the same as they were well received. Das Nair and Lincoln (2013) report that participants had an appreciation for the benefits that exist from a therapeutic point of view from having a group format, which was also the case here. The exercises, strategies and the content of the handbook will also largely remain unchanged. The focus of the COB-MS is on an holistic approach to cognitive rehabilitation.

Researchers have shied away from holistic and client-centred approaches in preference for repetition and remediation (Wilson, 1997) which are less likely to have any real impact on patient's lives. We can see evidence in the cognitive rehabilitation literature in populations with and without MS that research has tended to focus on one cognitive function (e.g. Cerasa et al., 2013) or used one modality, such as computerised training (e.g. Hildebrandt et al., 2007). The COB-MS takes a broader approach to rehabilitation. Cognitive abilities have been shown to correlate with other symptoms and functional difficulties that present in MS including fatigue and depression, as well as ability to maintain employment, social

activities, managing in the home and self-care (Finlayson, Impey, Nicolle, & Edwards, 1998). This indicates that an occupation-focused approach is likely to be particularly effective for this population. As clinicians may not have experience working with specific needs of a population of people who have MS and cognitive difficulties it would be essential that therapists be trained in the COB-MS before intervening with clients.

A limitation of this research was the small number of participants that were consulted. In addition, participants were female and thus it is not known if a male perspective on the COB-MS differs. For the participants with MS, there were no newly diagnosed participants and given the important suggestions around the timing of the intervention it would have been valuable to have had the voice of someone who was newly diagnosed. There may also be important views missing as the participants were diagnosed a relatively long time ago and were also of similar education levels and ages – the age band was quite narrow for both occupational therapists and participants with MS. Data saturation was achieved with occupational therapists but it is unlikely that saturations were reached with people with MS following one focus group in a single location.

Conclusion

The views of the COB-MS by people with MS and occupational therapists were largely positive but overcoming logistical challenges is key to successful intervention implementation. The range of difficulties seen in MS impacts all aspect of life and clearly suggests an urgent need for a targeted approach to cognitive rehabilitation intervention. The foundational evidence required to develop and refine the COB-MS has been established and it should serve this role, with further feasibility testing. This is the first known cognitive rehabilitation intervention in MS that focuses on occupation and participation and has the potential to positively impact the lives of people living with MS.

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References

- Amato, M. P., Zipoli, V., & Portaccio, E. (2006). Multiple sclerosis-related cognitive changes: A review of cross-sectional and longitudinal studies. *Journal of the Neurological Sciences*, 245(1), 41–46.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- British Psychological Society. (2008). *Conducting research with people not having capacity to consent to their participation: A practical guide for researchers*. London, UK: British Psychological Society.
- Cerasa, A., Gioia, M. C., Valentino, P., Nisticò, R., Chiriaco, C., Pirritano, D., ... & Bilotti, G. (2013). Computer-assisted cognitive rehabilitation of attention deficits for multiple sclerosis: A randomized trial with fMRI correlates. *Neurorehabilitation and Neural Repair*, 27(4), 284–295.
- Chiaravalloti, N. D., & DeLuca, J. (2008). Cognitive impairment in multiple sclerosis. *The Lancet Neurology*, 7(12), 1139–1151.
- Chiaravalloti, N. D., DeLuca, J., Moore, N. B., & Ricker, J. H. (2005). Treating learning impairments improves memory performance in multiple sclerosis: A randomized clinical trial. *Multiple Sclerosis*, 11(1), 58–68.
- Christiansen, C., Baum, C. M., & Bass, J. (2011). The person–environment–occupational performance model. In E. A. S. Duncan (Ed.), *Foundations for practice in occupational therapy* (5th ed., pp. 93–104). London, UK: Elsevier.
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: The new Medical Research Council guidance. *British Medical Journal*, 337, a1655.
- das Nair, R., & Lincoln, N. B. (2013). The effectiveness of memory rehabilitation following neurological disabilities: A qualitative inquiry of patient perspectives. *Neuropsychological Rehabilitation*, 23(4), 528–545.
- das Nair R., Martin K. J., & Lincoln, N. B. (2016). Memory rehabilitation for people with multiple sclerosis. *Cochrane Database of Systematic Reviews*, Issue 3. Art. No. CD008754. doi:10.1002/14651858.CD008754.pub3
- Finlayson, M., Impey, M. W., Nicolle, C., & Edwards, J. (1998). Self-care, productivity and leisure limitations of people with multiple sclerosis in Manitoba. *Canadian Journal of Occupational Therapy*, 65(5), 299–308.
- Goverover, Y., Chiaravalloti, N. D., O'Brien, A. R., & DeLuca, J. (2018). Evidenced-based cognitive rehabilitation for persons with multiple sclerosis: an updated review of the literature from 2007 to 2016. *Archives of physical medicine and rehabilitation*, 99(2), 390–407.
- Hildebrandt, H., Lanz, M., Hahn, H. K., Hoffmann, E., Schwarze, B., Schwendemann, G., & Kraus, J. A. (2007). Cognitive training in MS: Effects and relation to brain atrophy. *Restorative Neurology and Neuroscience*, 25(1), 33–43.
- Hynes, S. M. (2016). Internet, home-based cognitive and strategy training with older adults: A study to assess gains to daily life. *Aging Clinical and Experimental Research*, 28(5), 1003–1008.
- Hynes, S. M., Field, B., Ledgerd, R., Swinson, T., Wenborn, J., di Bona, L., & Orrell, M. (2015). Exploring the need for a new UK occupational therapy intervention for people with dementia and family carers: Community occupational therapy in dementia (COTiD). A focus group study. *Aging & Mental Health*, 20(7), 1–8.
- Kahlke, R. M. (2014). Generic qualitative approaches: Pitfalls and benefits of methodological mixology. *International Journal of Qualitative Methods*, 13(1), 37–52.
- Khan, F., & Amatya, B. (2017). Rehabilitation in multiple sclerosis: A systematic review of systematic reviews. *Archives of Physical Medicine and Rehabilitation*, 98(2), 353–367.
- Levine, B., Robertson, I. H., Clare, L., Carter, G., Hong, J., Wilson, B. A., & Stuss, D. T. (2000). Rehabilitation of executive functioning: An experimental–clinical validation of goal management training. *Journal of the International Neuropsychological Society*, 6(3), 299–312.
- NVivo Qualitative Data Analysis Software. Version 10, Melbourne, Australia: QSR International Pty Ltd, 2012.
- O'Brien, A. R., Chiaravalloti, N., Goverover, Y., & DeLuca, J. (2008). Evidenced-based cognitive rehabilitation for persons with multiple sclerosis: A review of the literature. *Archives of Physical Medicine and Rehabilitation*, 89(4), 761–769.
- Rosti-Otajärvi, E. M., & Hämäläinen, P. I. (2014). Neuropsychological rehabilitation for multiple sclerosis. *The Cochrane Library*.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334–340.
- Siepmann, T. A. M., Janssens, A. C. J. W., de Koning, I., Polman, C. H., Boringa, J. B., & Hintzen, R. Q. (2008). The role of disability and depression in cognitive functioning within 2 years after multiple sclerosis diagnosis. *Journal of Neurology*, 255(6), 910–916.
- Wilson, B. A. (1996). La réadaptation cognitive chez les cérébrolésés [Cognitive rehabilitation in brain injury patients]. In M. I. Botez (Ed.), *Neuropsychologie Clinique et Neurologie du Comportement* (2nd ed., pp. 637–652). Montreal, Canada: Les Presses de l'Université de Montréal.

Wilson, B. A. (1997). Cognitive rehabilitation: How it is and how it might be. *Journal of the International Neuropsychological Society*, 3(5), 487–496.

Appendix I. Focus group indicative topic guide (people with MS)

Note to facilitator:

- Begin with introductions and information about the group
 - location of washroom
 - length of the group
 - when there will be a break
 - what will happen during the group.
- Following this give description of the COB-MS programme
 - its purpose
 - structure of the programme
 - the content (does not have to be detailed)
 - use of the handbook.
- Ask for any questions on the programme or anything that needs to be clarified
- Follow the questions listed below to elicit views of participants. Some questions may require more prompting-prompt as necessary.
- Leave some time at the end for any further questions and to thank the participants

Indicative topics/questions:

1. What are your first impressions of the COB-MS programme?
2. What are your thoughts on the handbook?
 - a. Length
 - b. Activities
 - c. Layout
 - d. Content/amount of information
 - e. Anything else?
3. Can you see the COB-MS programme having some benefit?
 - a. Do you think it would meet your individual needs?
 - (i) If yes, how?
 - (ii) ii. If no, why?
 - b. Do you think there are enough sessions/too many?
 - c. Does it cover the areas important to you?
4. Any other advantages or positive things that you could see about having this programme?
5. Are there things that you dislike about what the programme?
6. What would you say was missing from this programme?
7. Is there anything else?
 - a. Any other feedback on this potential service?

- b. Is there anything that anybody feels that we have missed from the discussion we have had today?

Appendix II. Interview Indicative Topic Guide (Occupational Therapists)

Note to interviewer:

- Begin with introductions and information about the length of the interview
- Following this give description of the COB-MS programme
 - its purpose
 - structure of the programme
 - the content (does not have to be detailed)
 - use of the participant and facilitator's handbook.
- Ask for any questions on the programme or anything that needs to be clarified
- Follow the questions listed below to elicit views.
- Leave some time at the end for any further questions

Indicative topics/questions:

8. Do you have experience working with people with MS? And people with cognitive difficulties?
 - a. Please give some detail of your experience
 - b. How many years working as an OT?
 - c. How many working with people with MS?
 - d. How frequently do you come across cognitive difficulties in your practice?
9. What are your first impressions of the COB-MS programme?
10. What are your thoughts on the handbook?
 - a. Length
 - b. Activities – group and home
 - c. Amount of guidance provided
 - d. Layout
 - e. Content/amount of information, including the theoretical background
 - f. Anything else you would like included?
11. Can you see the COB-MS programme having some benefit for the people with MS you work with?
 - a. Do you think there are enough sessions/too many?
 - b. Does it cover the areas the you come across in your practice?
12. Any other advantages or positive things that you could see about having this programme?
13. Are there things that you dislike about what the programme?
14. What would you say was missing from this programme?

15. Do you think that this programme would be implemented in your workplace if proven effective?
- What would be the greatest facilitator?
 - What would be a barrier?
- c. Do you think it would require OT training? If so then what format would be best?
16. Is there any other feedback?

Appendix III.

Table 5. Example coding tree for theme I - Response to the intervention

Possible theme	Definition (which codes / data fit into theme)	Evidence / Some Examples from text (inc source: line number, page, which group)
Response to the Intervention	<ol style="list-style-type: none"> Positive Good fit Uncertainty Layout OT-Specific 	<p>2 "I couldn't believe it. It described my memory to a T." PMS5 p.1 line 23</p> <p>1 "It's a really great way to start by having a one to one session because I think you're gonna um have comfort, understanding and everything about the programme." PMS3 p.2 line 5-6</p> <p>1. "If you went through a programme like this, it might make it easier for people to really zero in on what they feel their problems are." PMS4, p.2 line 20-21</p> <p>1. "What I really like about it, it brings up the trending stuff now" [examples cannabis, mindfulness, apps] PMS1, p2 line 24-25</p> <p>1/2 "It's just I see them written down and see some strategies um being able to practice them is gonna be really important and so I'm just completely like thrilled" PMS 3, p3 line1-2</p> <p>1 "it's just going to be a great resource to have after people complete the programme as well, which I think is really great, and um, yeah super excited" PMS3, p3, line 10</p> <p>1. "The length is perfect. It's long enough to encompass everything you want, short enough and compact enough that it won't drag on and on." PMS2, p5, line 18-19</p> <p>4. "Plain English...just like we're having a conversation." PMS3, p7, line 8-9</p> <p>4. "The tone of your writing is very friendly and warm, good word choice, easy to understand." PMS 2, p8, line 19</p> <p>3. "Setting objectives, that's something I find very hard to do...I find it intimidating to be told I have to set goals." PMS 4, p10, line 5,7</p> <p>3. "It's not that I cannot do it [set goals] but I probably need a lot of help actually verbalising it" PMS 4, p10, line 10.</p> <p>4. "I have been to a multitude of self-development programmes and multitudes of business stuff – the illustrations and descriptions of meanings of how to set goals in this is comparable, if not, oh yeah, it's exactly as good, if not better...instead of making it very complicated...you've written it very simply... This is so well illustrated, written, on how to make a goal, it's just incredible" PMS 2, p10, line: 30-34. & p11, line 2-3</p> <p>2. "I like how there's a section on seeking new challenges...I'm not just gonna exist, I'm gonna live fully and I think I really like that." PMS 1, p 15, line 23-24</p> <p>2. "It's like a bible, basic instruction, it's like I'm so glad! ...it's gold, yeah, it's really gold." PMS1, p19, line 11, 30</p> <p>5. "It really was obviously client-centred, giving them the control and all those things I really, really like." OT 7, p2, line 24-25</p> <p>1. "To give details of different research that was done or experiments which I think again engages people in a different way where they go "oh! This has been shown to work" and it just kind of adds credibility to what you're saying and may be the breaking point of actually getting them to try strategies...I just felt that was a really nice thing to include." OT 7, p2, line 31-35</p> <p>5. "I also really liked that it was a group format where you had the ability to meet with the person individually to start and to end. I think that's a really important component." OT 7, p3, line 27-28</p> <p>4. "I definitely felt like a lot of the strategies, they were all really, really useful, really well outlined & comprehensive." OT 7, p4, line30-31</p> <p>5. "I really like that it's so occupation-based and occupation-focused." OT7, p5, line: 13</p>