

RESEARCH ARTICLE

Balance exercise facilitates everyday life for people with multiple sclerosis: A qualitative study

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Abstract

Objectives: The aim of this qualitative study was to describe the experience and perceived effects on everyday life for people with multiple sclerosis after participating in a balance exercise programme focusing on core stability, dual tasking, and sensory strategies (the CoDuSe programme).

Methods: A qualitative approach was chosen, using face-to-face interviews analysed with content analysis. Twenty-seven people with multiple sclerosis (20 women, 7 men) who had participated in the CoDuSe programme were included. All could walk 20 m with or without walking aids but could not walk further than 200 m. The CoDuSe programme was given twice weekly during a 7-week period.

Results: The analysis revealed five categories. *Learning to activate the core muscles* described how the participants gained knowledge of using their core muscles and transferred this core muscle activation into everyday life activities. *Improved bodily confidence* covered narratives of being more certain of the ability to control their bodies. *Easier and safer activities* showed how they could now perform activities in everyday life more safely and easily. *Increased independence and participation* involved the participants' improved ability and self-confidence to execute activities by themselves, as well as their increased participation in activities in daily living. *Experiences of the balance exercise programme* revealed that they found the programme novel and challenging.

The overall theme was *balance exercise facilitates everyday life*.

Conclusion: Participating in the CoDuSe programme was perceived to facilitate everyday life for people with multiple sclerosis. Taking part in the balance exercise programme taught the participants how to activate and use the core muscles, which increased their bodily confidence. Having increased bodily confidence helped them to perform everyday life activities with more ease and safety, which increased their independence and participation. The participants described the CoDuSe programme as novel and challenging, yet feasible.

KEYWORDS

exercise, multiple sclerosis, postural balance, qualitative research

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1 | INTRODUCTION

Multiple sclerosis (MS) is a chronic, neurological, most likely autoimmune disease that affects the myelin sheaths in the central nervous system (McAlpine & Compston, 2006). One common and often early symptom in people with MS is impaired balance (Martin et al., 2006; Soyuer, Mirza, & Erkorkmaz, 2006), which can lead to falls and in extension possible injuries (Gunn, Creanor, Haas, Marsden, & Freeman, 2014). Impaired balance leads to restrictions in everyday life and decreased participation in society (Cattaneo, Lamers, Bertoni, Feys, & Jonsdottir, 2017; Nilsagard, Carling, & Forsberg, 2012). Balance can be improved by balance exercise (Carling, Forsberg, Gunnarsson, & Nilsagard, 2017; Forsberg, von Koch, & Nilsagård, 2016; Gunn, Markevics, Haas, Marsden, & Freeman, 2015).

When evaluating a new intervention, it is essential to have several different aspects in mind, considering both objective and subjective evaluations. In order to properly highlight participants' experiences of taking part in a new intervention, qualitative evaluation is preferred (Campbell et al., 2000; Lewin, Glenton, & Oxman, 2009; Paul et al., 2014).

There are several previous qualitative evaluations of different types of exercise interventions for people with MS (Learmonth & Motl, 2016). However, to our knowledge, few studies that specifically evaluate interventions targeting balance have used both quantitative and qualitative approaches (Forsberg, Nilsagard, & Bostrom, 2015; Palacios-Cena et al., 2016; van der Linden et al., 2014). Two studies (Forsberg et al., 2015; Palacios-Cena et al., 2016) evaluated exercise interventions using video consoles (Wii and Kinect) to target balance control for people with mild to moderate MS. The interventions improved the participants' body control and positively affected balance and walking in everyday life. Participants exercising with Kinect described how they felt more independent in everyday life. Another study (van der Linden et al., 2014) reported perceived balance and posture improvement for wheelchair-using people with MS after 12 weeks of Pilates exercise, which gave an increased confidence in activities in everyday life. All three studies also reported that the participants had a positive attitude towards participation, and all three found the respective interventions feasible.

Maintaining balance is a complex task combining several different skills; this was the motivation behind the development of CoDuSe, a balance exercise programme containing core stability, dual tasking, and sensory strategies (Carling, Forsberg, Gunnarsson, et al., 2017; Forsberg et al., 2016). The purpose was to enhance balance and reduce the number of falls, and the concept was developed using an interactive process involving clinically experienced physiotherapists (PTs). The CoDuSe programme has been evaluated in two randomized controlled trials (RCTs), both of which reported enhanced balance after the intervention period in comparison with the control group (Carling, Forsberg, Gunnarsson, et al., 2017; Forsberg et al., 2016). A reduced fall frequency was also found (Carling, Forsberg, Gunnarsson, et al., 2017; Nilsagard, von Koch, Nilsson, & Forsberg, 2014). However, it is not clear whether the change in balance control can be transferred into everyday life. The aim of this study was therefore to describe the experience and perceived effects on everyday life for people with MS after participating in the CoDuSe programme.

2 | METHODS

2.1 | Design

Individual interviews were conducted and analysed with qualitative content analysis, using an inductive approach (Elo & Kyngäs, 2008; Krippendorff, 2013). The study was approved by the Regional Ethics Committee in Uppsala-Örebro (2014/302/1).

2.2 | Participants

Eligible participants were adults with MS who had participated in the RCT evaluating the CoDuSe programme during 2014 ($n = 51$; Carling, Forsberg, Gunnarsson, et al., 2017). The inclusion criteria were (a) having been diagnosed with MS by a neurologist according to the McDonald criteria (McDonald et al., 2001), (b) walking ability not exceeding 200 m (with or without a walking aid), and (c) ability to transfer between a wheelchair and a plinth with only slight assistance (in order to participate in the intervention). The CoDuSe programme was conducted in seven different centres in Sweden: five hospitals and two primary health care centres. Using a waiting list design, the participants were randomized to either an early or a late start of exercise, where the late start group served as the control group in the RCT. Because all participants took part in the balance exercise programme at some point, all were eligible for interviews.

For the interviews, a purposeful sample was used to achieve variety in sex, age, centre, and disease burden. Disease burden was assessed using the Expanded Disability Severity Scale (EDSS), which assigns scores on a range of 0–10 with a higher score representing greater disability (Kurtzke, 1983). We aimed to interview 50% of the 51 individuals in the RCT, and so 27 of these (20 women, 7 men) were invited to participate in this study via letter at the end of the intervention period.

2.3 | The CoDuSe programme

The CoDuSe programme was first developed for people with mild to moderate MS (Forsberg et al., 2016) and then modified for people with more advanced MS with the addition of home exercise (Carling, Forsberg, Gunnarsson, et al., 2017). The CoDuSe programme contains PT-led group exercise occasions twice a week during 7 weeks, with each session lasting 60 min. The first 30 min target the ability to activate the muscles of the central core of the body (core stability) and control them in different positions and during movements. Participants are then encouraged to maintain focus on core stability during individualized exercises targeting dual tasks (e.g., carrying a tray while getting up from a chair) and sensory strategies (e.g., walking on uneven surfaces). Further information regarding the balance exercise programme is available elsewhere (Carling, Forsberg, Gunnarsson, et al., 2017).

2.4 | Data collection

The participants were contacted by the first author (A. C.) by telephone to schedule an individual interview at a location chosen by the participant. The majority chose their home, three preferred a room at the local hospital, and one chose a local café. The interviews

were conducted 2–10 weeks after the intervention finished. A semistructured interview guide (Appendix A) was developed through discussion in the research group and then discussed with an experienced PT. The standardized initial question was always “You participated in the CoDuSe programme; can you tell me about your experience?” Follow-up questions were then asked in order to elicit information on both the participants' experiences of the balance exercise programme and their perceptions of the effects of the balance exercise programme on their everyday lives.

The first author (A. C.) conducted all interviews. The co-authors listened to the interviews throughout the period of data collection, in order to be able to give feedback if necessary. Interviews lasted 10–37 min (mean 22 min) and were recorded and transcribed verbatim.

2.5 | Data analysis

A qualitative content analysis (Krippendorff, 2013) was performed as described by Elo and Kyngäs (2008). In the preparation phase, the whole interviews were selected as unit of analysis, and the manifest content (the text) was analysed. The interviews were listened to and read through several times in their entirety to get a sense of the material as a whole and to correct any errors or ambiguities in the transcriptions. After preparing the data, the organization of the data continued. Open codes based on the purpose of the study were written down and then fused together to create a coding sheet. The codes were then grouped into subcategories, in order to describe the similarities and differences between the participants' statements. The subcategories were grouped into categories, and the categories were abstracted to generate a general description using an overall theme. There was a constant moving back and forth in the process. The results are described through the content of the categories, and the content of the categories is described through subcategories. Authentic quotations were chosen to illustrate and support the results and to increase the trustworthiness.

The analysis was primarily conducted by the first author (A. C.), but every step in the process was continuously discussed with the co-authors until consensus was reached. All authors are PTs with 10–23 years of clinical experience in neurological physiotherapy and 3–18 years of experience in qualitative research. Version 10 of the NVivo 10 software package was used during the analytical process.

3 | RESULTS

3.1 | Demographics of the participants

All of the 27 people invited to participate agreed to do so. Their mean age was 59 years (range 49–76), and their EDSS scores ranged from 4 (*significant disability but self-sufficient*) to 7.5 (*unable to take more than a few steps*), with a median score of 6 (*requires walking aid to walk 100 m*). Demographic information is given in Table 1.

3.2 | Balance exercise facilitates everyday life

The analysis revealed five categories, four regarding perceived effects and one concerning the experience of participating in the balance

TABLE 1 Demographic characteristics of the participants

| Variable | Total (n = 27) |
|-----------------------------|----------------|
| Age | 59 (7.9) |
| Sex | |
| Female | 20 (74%) |
| Male | 7 (26%) |
| Type of MS | |
| Relapsing remitting MS | 4 (15%) |
| Primary progressive MS | 5 (18%) |
| Secondary progressive MS | 18 (67%) |
| EDSS score | 6 (4.0–7.5) |
| Centre | |
| Hospital | 22 (81%) |
| Primary health care centres | 5 (19%) |

Note. For categorical variables, n (%) is presented. For continuous variables, mean (SD)/median (min–max) is presented. MS: multiple sclerosis; EDSS: Expanded Disability Severity Scale.

exercise programme. Each category was formed of two to four subcategories. The categories on perceived effects all related to each other; the relationship between them is shown in Figure 1. The five categories together built the overall theme, “balance exercise facilitates everyday life,” which encompassed the participants' descriptions of how taking part in the balance exercise programme had increased their ability to perform and control everyday life activities (Figure 1).

3.3 | Learning to activate the core muscles

3.3.1 | Novel awareness of the core muscles

The participants reported that taking part in the balance exercise programme gave them a novel awareness of their core muscles. They described learning how to activate them, how to isolate the contractions in different positions, and the importance of this for basic activities in everyday life, such as in transfers or while walking. This new knowledge took time and constant reminders to learn, both of which they received from the PT-led balance exercise sessions.

And you noticed fairly early that finding those muscles got results, so it helped. Even if no-one else noticed, I noticed. And even though it was a very small thing, for me it felt huge. (Participant 4)

3.3.2 | Automated use of the core muscles

Being able to activate their core muscles allowed the participants to use these muscles during the day, thus facilitating their different activities in everyday life. They described how they went from having to actively think about activating their core muscles to being able to do this automatically.

Actually, to me the core stability stuff that you do at first seemed a bit ridiculous; however, you do use the core stability without really thinking about it. You need it in almost all situations—when you're walking, sitting down, or getting up from a sitting position. (Participant 17)

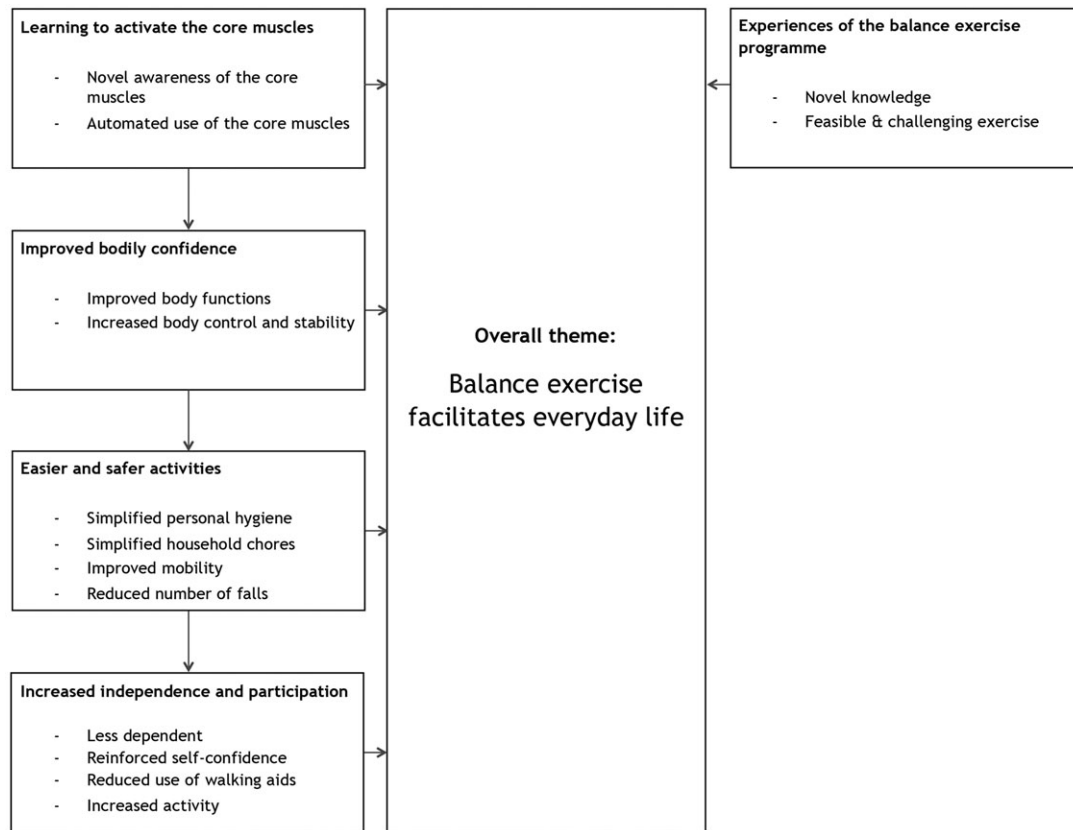


FIGURE 1 Schematic view over categories, including subcategories, building the overall theme *balance exercise facilitates everyday life*

3.4 | Improved bodily confidence

3.4.1 | Improved body functions

Having a greater awareness of their core muscles led to a feeling of control over their whole body, as well as bodily functions such as balance, strength, and postural control. Participants described how their posture had improved and their stability had increased in sitting and standing. They also described less wobbling and an enhanced ability to fend the body in different situations.

I used to always have my wheelchair indoors, because I didn't have the strength to sit in a regular chair. Now I usually sit in a regular chair. It's got better because I've been doing the exercises. (Participant 26)

3.4.2 | Increased body control and stability

The participants felt stronger and had a greater feeling of control over their arms and legs. Because they were able to control their body, they were able to take things slower and at a more comfortable pace. They felt more calm and controlled in different situations, able to trust their body due to the increased control.

I stood, on my own steam, and felt I could now say to my body: 'OK, I'm the one in charge now.' And I stood here and ... and just the feeling, it was almost an ah-ha moment, I swear! And so that's when I learned that. And that's useful to me all the time, every day. (Participant 18)

3.5 | Easier and safer activities

3.5.1 | Simplified personal hygiene

Enhanced body control generated enhanced control in daily activities. Several participants described how this simplified their daily activities, for example, when taking care of their personal hygiene, or said that it was less tiring to get dressed, brush their teeth, walk to the bathroom, and stand up while taking a shower.

I've started blow-drying my hair. Before, I never had the energy to stand and blow-dry my hair. (Participant 7)

3.5.2 | Simplified household chores

The participants described increased energy in everyday life making it easier to perform household chores such as doing the washing up, getting something from the shelves, ironing, carrying things, standing up to bake bread, and vacuuming without needing to take breaks. Not having to plan every move also made for an easier life.

I have stamina—I can stand for long periods, stand and work, and my body is stable. I can stand where I'm standing, so to speak, so that... yeah... Without feeling that I'm sort of crumpling... it's like, 'I can do this now, I can tense my body so that I can stand and do something—I can work.' (Participant 2)

3.5.3 | Improved mobility

Many participants mentioned having a steadier walk, as well as a steadier stance. They found themselves more able to walk on different surfaces and to walk faster, straighter, or for longer. Having the ability to transfer between places was also described as being easier and safer, both indoors and outdoors.

But I feel—particularly now when I get into the car... before, it was a such huge hassle—I had to shift my leg and everything. But I don't need to do that anymore, and it's amazing! (Participant 23)

3.5.4 | Reduced number of falls

Being able to control their bodies in different activities had led to a reduced number of falls. Some participants even said that they had not experienced any falls at all after the balance exercise programme.

I don't fall at all now... not any more, because my core is always engaged. (Participant 27)

3.6 | Increased independence and participation

3.6.1 | Less dependent

Increased body control in everyday life situations enhanced the participants' independence as well as their participation. They described a freedom in being able to execute activities by themselves, instead of having to get help from someone like before. Some described how they now needed less help from the community home support, their personal assistants, or members of their family.

One thing I had to deal with before that was that my balance wasn't good enough for me to put petrol in my car by myself. The way things are now, I can fill up my car without needing to ask for help. (Participant 17)

3.6.2 | Reinforced self-confidence

Taking part in the balance exercise programme gave the participants increased mental well-being. This in turn gave them increased confidence in themselves, self-determination, and control of their lives. A reinforced self-confidence produced feelings of trust in their ability to accomplish tasks they had not been able to manage before. This also gave them a drive to plan activities that had previously been unthinkable and to plan for the future. One participant described how she felt less ashamed in public places, due to her reinforced self-confidence.

It's easier to do things; I think it's easier for me to have the courage to take my electric wheelchair and just go, now that I've got more stability. That I can just leave by myself—when I need to go to choir practice or something like that. I don't feel unsafe there now—everything functions more easily now. It's like I now feel freer. (Participant 16)

3.6.3 | Reduced use of walking aids

The use of walking aids was also reduced. Several participants described how their enhanced control of their body and daily activities made them feel safe while walking, as they no longer had to use a walking aid.

When I started doing the exercises, I'd get there by walking with my rolling walker, but I don't use it now. I can manage short trips downtown and back without using the rolling walker. (Participant 7)

3.6.4 | Increased activity

The participants described how they were now able to participate in activities that previously had been out of the question. They stopped avoiding situations and were able to resume previously loved activities such as baking or walking in the garden. They had both the ability and the energy to join their families in several different kinds of events.

I have four young boys, so there's lots of playing and being outdoors, and fetching them from different places. Well, they thought I participated more—everything went easier, and I participated more. They could see that it was doing me good, you could say. (Participant 10)

3.7 | Experiences of the balance exercise programme

3.7.1 | Novel knowledge

Most of the participants considered that twice-weekly group exercise occasions for 7 weeks were sufficient, and they could fit the balance exercise programme into their everyday schedules without too many alterations. However, a few of the participants had difficulty recovering between the group exercise occasions, resulting in them having to adjust their weekly chores relative to the days of exercise. The main content of the CoDuSe programme, the core stability, was new to many of them. Most of them found the content suitable to target balance. The balance exercise programme was challenging in terms of both body function and concentration.

A new type of exercise for me. I didn't need to do the exercises until I was blue in the face; instead, when I went home, I'd feel mentally tired. It demanded a lot of concentration. You worked as much with your mind as with your body. It was inspiring. (Participant 8)

3.7.2 | Feasible and challenging exercise

The participants appreciated that the movements in the balance exercise programme were often small and precise and that the content was individually adjusted for each of them. This in turn made it possible to distribute their energy throughout the whole length of each session. However, some of the participants described how their energy levels were lower at the end of the sessions. Although the participants all had different prerequisites and physical functions, they were able

to get individual adjustments and recommendations from the PTs, helping them to exercise on their own individual levels. This was described as important, because the exercise was considered specific and was for many a brand new way to approach balance exercise. They dared to test their limits, which gave them a positive feeling when succeeding at a given task.

I could do things I never dared to do on my own—stand up without holding onto something, and whack a balloon back and forth. For me, this was fantastic! (Participant 18)

4 | DISCUSSION

This qualitative interview study describes how exercising with the CoDuSe programme can facilitate everyday life for people with MS. The participants achieved an increased awareness of their core muscles and were able to transfer this into daily activities. Learning to activate the core, and to automate this, made them feel more in control of their body and bodily functions, resulting in bodily confidence. Their increased control in everyday activities led to increased independence as well as participation. Taking part in the balance exercise programme was considered positive; the exercise was novel to them, and they considered it challenging but feasible.

Previous studies of the CoDuSe programme have reported increased dynamic balance and reduced numbers of falls (Carling, Forsberg, Gunnarsson, et al., 2017; Nilsagard et al., 2014). However, these studies found no statistically significant changes in core stability or walking ability, both of which were perceived by participants in this study as having been affected by the balance exercise programme. A possible explanation for the difference may be that several of the quantitative outcome measures were dependent on time, requiring the participants to perform a task as quickly as possible. As described in the interviews, the participants perceived that they had gained enhanced control over their bodies and were able to perform activities at their own speed, indicating enhanced quality rather than faster execution. The complementary results of the two studies indicate the importance of using both quantitative and qualitative evaluations of interventions (Campbell et al., 2000; Paul et al., 2014).

Being able to control the core muscles while performing functional tasks that required dual tasking or sensory strategies (targeted in the CoDuSe programme) was considered important by the participants. Even though the evidence for core stability exercise in people with MS has been equivocal (Fox, Hough, Creanor, Gear, & Freeman, 2016; Freeman et al., 2010), the participants in this study perceived that the balance exercise programme containing core stability as one component made them feel safer while performing different activities in everyday life. Falling has been reported to occur most frequently during everyday activities (Carling, Forsberg, & Nilsagard, 2018; Gunn et al., 2014), and it is therefore of great value to provide interventions containing challenges similar to those present in everyday life.

Previous studies have reported restricted participation among people with MS (Cattaneo et al., 2017; Nilsagard et al., 2012), with this restriction increasing at higher EDSS scores (Cattaneo et al., 2017).

Qualitative studies have shown improved participation among people with MS after intervention periods involving progressive resistance training (Dodd, Taylor, Denisenko, & Prasad, 2006; Giacobbi, Dietrich, Larson, & White, 2012), wheelchair Pilates (van der Linden et al., 2014), aqua fitness (Brown, Kitchen, & Nicoll, 2012), and group exercise classes (Learmonth, Marshall-McKenna, Paul, Mattison, & Miller, 2013); and now, we also report improvement after a balance exercise programme. Increased social participation and feelings of self-management and control were identified in a review as some of the most commonly perceived beneficial consequences of physical activity and exercise (Learmonth & Motl, 2016). Both avoidance of social activities and isolation are associated with lower health-related quality of life, whereas high physical health-related quality of life is associated with social participation (Mikula et al., 2015). The importance of enhancing participation for people with MS, especially those with a higher EDSS, is therefore of great value. Having improved control of one's body as well as being more independent may imply enhanced participation, something that the balance exercise programme was able to provide. The CoDuSe programme can be a way for people with MS to feel more secure, increase their self-confidence, and enhance both their independence and their participation in everyday life.

Facilitating factors for physical activity and exercise in people with MS can be both environmental and personal (Learmonth & Motl, 2016). The participants in this study described several environmental facilitators, such as the knowledge and engagement of the PTs. Being able to complete a balance challenge requires knowledgeable and skilled PTs who are motivating, who can progress the exercise individually for each participant, and who can provide accurate feedback. This also made it possible for a wide range of participants to take part in the intervention, despite different functional level.

4.1 | Methodological considerations

When evaluating exercise interventions, different aspects provide useful information. Using quantitative measures requires the researcher to decide which outcome measure is most likely to reflect the expected effects. Interviews with open-ended questions can be used to elicit the effects on each participant. This study focused on evaluating activity and participation where outcome measures are sparse, and a qualitative method was considered most useful. Several different components were considered in order to achieve trustworthiness (Lincoln & Guba, 1985): credibility, which deals with the focus of the research and how well the data and analysis address the intended focus; dependability, which is concerned with the stability of the data over time; and transferability, which describes how the results can be transferred to other persons and populations. Individual face-to-face interviews were considered an appropriate method to elicit the participants' own perceived effects and experiences from the balance exercise programme. When selecting the participants, several aspects (sex, age, centre, and EDSS score) were taken into consideration in order to establish credibility. In terms of these aspects, the sample in the present study was representative of the whole intervention sample (Carling, Forsberg, Gunnarsson, et al., 2017). Having this strategic sample strengthens the transferability to other people with MS with similar body function and living conditions. An interview guide was

used in order to establish confirmability and dependability. The guide was used as a checklist to cover all the desired areas and was used only as an aid in the conversation; the participants controlled the interview, not the interview guide.

A limitation was that the first author was also in charge of the intervention and measure occasions at several different centres, which meant that some of the participants had already met A. C. during the intervention. This might have affected their answers, but they were encouraged to contribute both positive and negative information about the perceived effects and the exercise intervention. Being part of a group and exercising with that group could be considered as a contributing factor in the participants' having had such a positive perception of the exercise. Another possible limitation is that participation in the balance exercise programme was voluntary, and so the participants had an interest in and probably a positive attitude towards exercise even before the intervention started. Although this was a new way of exercise for the participants and both positive and negative aspects were asked for, almost all the feedback was positive, in line with other studies (Brown et al., 2012; Forsberg et al., 2016). Because the participants were encouraged to maintain focus on core stability during the exercises targeting dual tasks and sensory strategies, core stability was mentioned frequently during the interviews; however, comments on the whole balance exercise programme were asked for and evaluated.

In conclusion, participation in the CoDuSe programme was perceived to facilitate everyday life among people with MS. The participants acquired new knowledge of how to use their core muscles to facilitate activities in daily living, helping them to be more independent, as well as improved ability to participate in everyday life situations. All of this contributed to an easier and safer everyday life.

4.2 | Implication for physiotherapy practice

The CoDuSe programme is a balance exercise programme conducted in groups, feasible for people with MS. The balance exercise programme was perceived to enhance activities and participation, reduce number of falls, and facilitate everyday life for people with MS; all of these aspects are important to address in clinical physiotherapy practice.

AUTHOR CONTRIBUTIONS

All authors have made substantial contributions to conception and design, or analysis and interpretation of data. Anna Carling performed all the interviews. All authors were involved in drafting the manuscript or revising it critically for important intellectual content. All authors have given final approval of the version to be published. All authors agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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APPENDIX A INTERVIEW GUIDE

Initial question:

You participated in the CoDuSe programme; can you tell me about your experience?

Follow-up questions:

Do you think that the balance exercise programme has affected you, and if so, how?

Can your everyday life benefit from what you have learnt during the balance exercise programme and if so, can you please explain how?

Is there anything else you would like to tell me regarding the possible effects from the balance exercise programme that I haven't already asked you about?