Impaired balance and fall risk in people with multiple sclerosis
Balance is beautiful
Impaired balance and fall risk in people with multiple sclerosis
Abstract


The symptoms from the neurological disease multiple sclerosis vary from person to person and over time. Impaired balance is common in people with multiple sclerosis and can lead to falls. Fall frequency is high in people with multiple sclerosis, above 50%. Multiple sclerosis affects not only the person having the disease but also their next of kin. To be able to reduce fall risk it is important to know when, why and where people with multiple sclerosis fall, and how to improve balance and reduce falls with exercise. It is also important to know how the falls affect the residing next of kin to people with multiple sclerosis.

The overall aim of this thesis was to gain enhanced knowledge by investigating when and why people with MS fall and how these falls possibly affect their next of kin, and also to evaluate the effects and perceptions of participating in a specific balance exercise.

Data were gathered using four different data collections, and this thesis contains both qualitative and quantitative data.

The major finding in this thesis is that people with multiple sclerosis fall in the course of everyday life activities, most often in their own homes due to various intrinsic and extrinsic factors. Balance can be improved and falls reduced and everyday life may be made easier and facilitated after participating in the CoDuSe balance exercise. This is important also for the next of kin, since they are adapting, adjusting and renouncing their activities due to the falls of the PwMS, in order to make it work for the whole family.

Keywords: Balance, exercise, falls, falls efficacy, gait, multiple sclerosis, next of kin, physiotherapy, qualitative research, randomized controlled trial

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List of publications

This thesis is based on four publications:


Carling A, Nilsagård Y, Forsberg A. Making it work: experience of living with a person who falls due to multiple sclerosis. *Disability and Rehabilitation* Accepted August 16th 2018.
## Abbreviations

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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>2MWT</td>
<td>2-minute walk test</td>
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<tr>
<td>10WT</td>
<td>10-metre walk test</td>
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<tr>
<td>ABC</td>
<td>Activity-specific balance confidence</td>
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<tr>
<td>ADL</td>
<td>Activities of daily living</td>
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<tr>
<td>BBS</td>
<td>Berg Balance Scale</td>
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<tr>
<td>CI</td>
<td>Confidence interval</td>
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<tr>
<td>CoDuSe</td>
<td>Core stability, Dual task, Sensory strategies</td>
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<tr>
<td>CNS</td>
<td>Central nervous system</td>
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<tr>
<td>EDSS</td>
<td>Expanded Disability Status Scale</td>
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<tr>
<td>ES</td>
<td>Effect size</td>
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<tr>
<td>FES-I</td>
<td>Falls Efficacy Scale–International</td>
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<tr>
<td>FGA</td>
<td>Functional gait assessment</td>
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<tr>
<td>FSMC</td>
<td>The Fatigue Scale for Motor and Cognitive Function</td>
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<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<tr>
<td>MS</td>
<td>Multiple sclerosis</td>
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<tr>
<td>MSWS</td>
<td>12-item Multiple Sclerosis Walking Scale</td>
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<tr>
<td>MRI</td>
<td>Magnetic resonance imaging</td>
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<tr>
<td>NEDA</td>
<td>No evidence of disease activity</td>
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<tr>
<td>OR</td>
<td>Odds ratio</td>
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<tr>
<td>PPMS</td>
<td>Primary progressive multiple sclerosis</td>
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<tr>
<td>PwMS</td>
<td>Person/people with multiple sclerosis</td>
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<tr>
<td>RCT</td>
<td>Randomized controlled trial</td>
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<tr>
<td>RRMS</td>
<td>Relapsing–remitting multiple sclerosis</td>
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<tr>
<td>SD</td>
<td>Standard deviation</td>
</tr>
<tr>
<td>SDMT</td>
<td>Symbol Digits Modalities Test</td>
</tr>
<tr>
<td>SEM</td>
<td>Standard error of the mean</td>
</tr>
<tr>
<td>SPMS</td>
<td>Secondary progressive multiple sclerosis</td>
</tr>
<tr>
<td>TIS</td>
<td>Trunk Impairment Scale</td>
</tr>
<tr>
<td>TstS</td>
<td>Timed sit to stand</td>
</tr>
<tr>
<td>TUG</td>
<td>Timed up and go</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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</table>
Introduction

I started working as a physiotherapist within the neurological field in 2007, at Örebro University Hospital, mostly as a physiotherapist in the multiple sclerosis (MS) team. Being a physiotherapist working with people with MS allows the opportunity to meet with them over time. The disease course of MS may involve a variety of symptoms over time, and some individuals present a progressive burden of neurological deficits. Having the opportunity to help each individual with the physical symptoms they find most important to deal with at that particular moment can be a satisfying task. However, when accorded the trust to help a person to improve or maintain their impaired physical skills, it is important to know what would be the most suitable treatment/intervention to offer.

During my time in the MS team, I had the opportunity to participate in the data collection of two different exercise studies including people with MS. Seeing close up what research could mean for the participating patients, the people that I met every day in my routine clinical life, made me think of research in a brand-new way. The researcher performing the studies including ‘my’ patients inspired me to think big. For the first time, it occurred to me that maybe I could be a researcher. Keeping my patients’ best interest at heart has always been a motivation and an approach for me as a physiotherapist. But, how could I know what the patients’ best interests were at all times if there were no research to provide guidance in the subject? That question was the genesis of this thesis, and the driving force also in the research: to keep the patients’ best interests at heart.
Background

Multiple sclerosis

Multiple sclerosis (MS) is a chronic neurological disease that affects the central nervous system (CNS). It is considered an autoimmune disease but the underlying mechanisms are not yet fully understood, and target antigens remain to be identified. Symptoms occur upon disruption of nerve signal transmission due to immune-mediated demyelination. Myelin may be partially restored by remyelination, while axonal degeneration causes irreversible neuronal damage seen as multiple scars, also called MS lesions or MS plaques. The lesions mostly occur in the white matter, often perpendicular to the ventricular system in the brain or in the spinal cord. The locations of lesions determine which functions are affected, for example motor, sensory or cognitive.

The cause of the disease is not yet established, but most likely it is the result of a complex interplay of genetics and environmental factors. Various risk factors have been suggested, such as smoking, low level of vitamin D, previous Epstein-Barr virus infection and genetics.

There is no one single specific diagnostic test to establish MS; instead, the diagnosis is criterion-based, that is, on the McDonald criteria. The basic diagnostic criterion is evidence of distribution of MS lesions in time and space. Aggregation of neurological symptoms, the course of the disease, magnetic resonance imaging (MRI) and a detection of inflammation in the spinal fluid are considered. In 2010 the McDonald criteria were revised, making it possible to diagnose MS at its clinical onset, using MRI.

MS is a heterogenic disease and the course varies from person to person. There are different types of MS. Approximately 90% of MS patients have relapsing–remitting MS (RRMS) from onset and experience periods of transient neurological symptoms, called relapses or exacerbations. A relapse lasts between 24 hours and weeks up to months before partial or complete recovery. Natural history data show that RRMS commonly transfers into a secondary progressive MS (SPMS) course in time (11–21 years), with continuing loss of functions not related to relapses. SPMS is diagnosed retrospectively by a history of gradual worsening. A subset of people with MS (PwMS) (approximately 10%) have a progressive course from onset,
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It is debated whether this clinical subtype differs from the others in terms of immunopathology.\textsuperscript{12}

MS onset often occurs early in life, typically between the ages of 20 and 40 years. People with RRMS are younger at onset (approximately 30 years)\textsuperscript{14} compared to people with PPMS (approximately 40 years).\textsuperscript{13, 15} Women are more than twice as likely to be affected, compared with men,\textsuperscript{16-18} a ratio that has increased over time in Sweden, from 1.7:1 for people born in the 1930s to 2.67:1 for people born in the 1980s.\textsuperscript{19} Globally, an estimation made in 2013 indicates that 2.3 million people have MS.\textsuperscript{20} The highest incidence and prevalence are seen in North America and in Europe,\textsuperscript{20, 21, 22} and migrations studies suggest that environmental factors before adolescence are important for MS risk.\textsuperscript{23-25} In Sweden, nearly 18 500 people are diagnosed with MS.\textsuperscript{26}

In the last 20 years development of disease-modifying treatments for MS has been extensive. By different mechanisms of action such treatments reduce the inflammatory activity in the CNS, preventing myelin and axonal disruption.\textsuperscript{27} Today, treatment options are highly efficient, and no evidence of disease activity (NEDA) has been proposed as a goal to prevent future disease progression. Still, there is no medication available to cure MS. Besides medication, physical rehabilitation has an important role in maintaining and improving physical abilities.\textsuperscript{28} The World Health Organization (WHO) describes rehabilitation as a process that enables individuals to identify problems and to reach their optimal ability, aiming to facilitate independence and social integration.\textsuperscript{29} Rehabilitation due to a neurological disease such as MS is targeted at maintaining and possibly improving the residual physical functions, with the aim of preserving the individuals’ personal and social activities. Impaired balance and falls are often symptoms for physiotherapists to evaluate and work to improve together with the individual affected.

Exercise may promote brain health in disease by enhancement of neurobiological processes such as neuronal protection, regeneration and plasticity.\textsuperscript{30, 31} It is suggested that motor rehabilitation induces structural plasticity in PwMS, and the exercise should be task-dependent and selective in its targets.\textsuperscript{32}
Clinical evaluation of MS severity

Worldwide, neurological impairment and MS severity are evaluated by neurologists using the Expanded Disability Status Scale (EDSS).\(^3\) The scale was developed in 1983 and ranges from 0 to 10, in steps of 0.5, where 0 equals a normal neurological examination and 10 represents death due to MS (Figure 1). Scores of 0–3.5 are based on the examination of eight different functional systems: pyramidal functions, cerebellar functions, brain-stem functions, sensory functions, bowel and bladder functions, visual functions, cerebral (or mental) functions and other. Scores from 4 and above are based on the person’s walking ability, the actual distance a person can walk and the need of a walking aid. For practical reasons, walking distance is often estimated in MS care and not always tested. MS can be graded as mild at EDSS 0 to 3.5, moderate at EDSS 4.0 to 5.5 and severe at 6.0 to 9.5.\(^4\) When using a patient-administered EDSS, the patients answer questions covering the eight functional systems as well as walking ability, and the answers are interpreted by a neurologist as an EDSS score.\(^5\) However, difficulties for PwMS to correctly estimate their maximum walking distance may have impact on the evaluation.\(^6,\)\(^7\)

![Figure 1. Illustration of the EDSS scores.\(^3\)](image.png)

Balance

Balance is a complex task that requires several different skills, motor (e.g. strength and flexibility), sensory (e.g. vestibular system and proprioception) and cognitive (e.g. concentration and attention).\(^8\) Interactions between these functions are integrated to keep balance. Balance is a commonly used term, but there is no universally accepted definition.\(^8\) ‘Balance’ can be seen as a blanket term which encompasses postural control,\(^9\) stability,\(^9\) balance control\(^8\) and alignment.\(^8\) In this thesis, balance will be regarded from the
A perspective that an interaction between the individual, the task performed and environmental factors is required to be able to maintain balance.\textsuperscript{38}

Although there is no specific code for balance in the International Classification of Functioning, Disability and Health (ICF), the complexity of balance can be understood through the components of the framework;\textsuperscript{40} see Figure 2. Balance can be affected by impaired body functions or structures. Balance is also dependent on which activity is to be performed, which in turn can affect participation. Personal factors (such as balance confidence) and environmental factors also contribute to achievement of balance.

\textit{Figure 2. International Classification of Functioning, Disability and Health.}\textsuperscript{40}

Movements of the body are planned and programmed in the cerebral cortex. The motor cortex sends its commands (motor output) to the skeletal muscles of the body where the actual movement is performed. Information regarding the planning of movement is also sent from the cerebral cortex to the cerebellum, which is the motor control centre of the body. The cerebellum coordinates and regulates posture, movement and balance. The cerebellum also receives sensory input from the muscle spindles and the Golgi tendon organs, which give feedback of the muscle length, speed and tension; from vision; from proprioception via the joint receptors; and from sensory touch via the cutaneous receptors. After receiving the sensory input, the cerebellum evaluates the performed movements, and adjusts the position of the body parts, if necessary.\textsuperscript{38} See Figure 3.
There are different aspects to balance, depending on the task to be performed. Static balance is the ability to maintain an upright position without changing the base of support; it is characterized by small amounts of spontaneous postural sway. Dynamic balance is the ability to maintain balance during movement. Proactive balance is the ability to prepare the body for the movement before the movement is performed, which can also be referred to as feed forward. To minimize instability in a movement, the stabilizing muscles are activated, since the voluntary movements in themselves can be destabilizing. Reactive balance, the opposite of preparing for movement, occurs when the body has to react to something unforeseen. This represents the ability to recover balance after an unexpected disturbance and to move defensively in order to maintain balance and avoid falls.38
Measuring balance
In clinical practice as well as in research it is important to measure balance. Measuring different aspects of balance provides a better understanding and description of each individual’s strengths and limitations and enables the practitioner to evaluate possible changes after an intervention. Outcome measures can be objective or subjective. It is also vital to select a measure that reflects impaired body function or structure, limitation of activity or restriction of participation. The ICF model has been recommended to structure assessment of imbalance in PwMS.41 The measures must be reliable (i.e. consistent and repeatable) and valid for the group of people and condition being evaluated.

Impaired balance in MS
Impaired balance is a common and often early symptom in PwMS.42 Over 80% of the PwMS in a study reported their balance to be impaired, 15% reported a fluctuation of balance, while 67% reported the impairment to be constant.43 In a review, Cameron and Lord44 stated three different aspects of balance that were typically impaired for PwMS.

First, they described how PwMS have a decreased ability to maintain position. PwMS were found to have an increased postural sway and more difficulties in maintaining position when the base of support is reduced or limited, compared to healthy controls. It was also reported that PwMS with a more severe impairment (a higher EDSS score) have an increased postural sway compared to those with a mild impairment. Having a progressive type of MS also indicates more postural sway compared to those with RRMS.44 PwMS do not use the same strategies to maintain balance as age-matched healthy controls without walking limitations do, hence the increased sway.45

Second,44 PwMS are described as having limited and slow movement toward their limits of stability. When trying to reach or step, PwMS move less far or less quickly compared to healthy controls. PwMS also have a reduced functional reach distance.

Third, PwMS have delayed responses to postural displacements or perturbations. They have poorer trunk control and delayed postural responses when the surface is moving.44 It has also been reported that PwMS have impaired trunk stability while sitting on an unstable surface, compared to healthy controls.46
Stability of the trunk, or trunk control, comprises coordination of active (i.e. muscles), passive (i.e. lumbar spine) and control (i.e. neurological system) aspects. Muscles that are believed to create trunk control are the transvers abdominis (works as a corset around the tummy), the multifidus (lies along the back of the spine connecting one vertebra to the other) and the pelvic floor muscles (forming a sling from the pubic bone at the front to the base of the spine at the rear). All of the trunk muscles are valuable and significant for the control of the trunk; it is the situation and position of the body that determines which muscles are most important at a given time. The core muscles serve as a muscular corset that works as a unit to stabilize the body and spine; it serves as the centre of movements in the limbs and body. Stability and movement of the body are critically dependent on the coordination of all the muscles which together form the core. In order to use the same terminology as reference articles to the intervention presented later, the term trunk control will be used synonymously with core stability in this thesis.

The three aspects of impairments reported in PwMS include static and dynamic, as well as proactive and reactive, balance. More recently, a fourth aspect has been identified to also be typically impaired for PwMS, namely, dual tasking. Having to divide one’s attention while performing a balance-requiring task can affect the balance negatively for PwMS. Impaired balance can lead to restrictions in everyday life as well as decreased participation in society. A systematic review reported that postural control in PwMS is impaired, regardless of the complexity of the task performed.

As stated earlier, balance requires motor, sensory and cognitive skills to be attained. All of these skills can be affected by MS, as visualized in Figure 4.
Figure 4. MS can affect different aspects in the interaction between the brain and the motor and sensory systems required to achieve balance.

Falls

The ultimate consequence of not being able to maintain one’s balance is to experience a fall. Falls are, like balance function, considered to be of complex nature. The definition of falls varies. In this thesis a fall is defined as ‘an unexpected event in which participants come to rest on the ground, floor, or a lower level,’ as recommended by international expert consensus. A person who has experienced a fall within a defined period of time is defined as a faller and a person who has not experienced a fall within that same period of time is defined as a non-faller. A frequent faller is a person who has experienced more than one fall during the same period of time.
The time period differs between studies. In this thesis, a faller is defined as a person who falls within a three-month period (study I) or within a seven-week period (study II).

**Falls in MS**

Fall risk in MS is generally high. A fall frequency of 56% during a three-month period has been reported for people with an EDSS score between 1.5 and 7.0 in an international meta-analysis, indicating that over half of PwMS who are ambulatory fall at least once in a span of three months.\(^57\) Of those reporting a fall, 37% were frequent fallers.\(^57\) Most of the falls have been retrospectively reported to occur indoors (65%) during daytime (75%).\(^57\) There is not a linear progression of the risk for falls, correlated to the EDSS score. A peak for fall risk has been suggested at EDSS score 4.0 and 6.0 (see Figure 5), scores in which walking transitions are likely.\(^57\)

![Figure 5. Odds ratio (OR) for falls according to EDSS score.\(^57\)](image)

Most of the falls, 80%, have been reported to occur during transfers, most frequently during walking (60%).\(^58\) Men fall more frequently than women.\(^59, 60\) Previously published studies describing the circumstances of falls in PwMS have collected data retrospectively after the fall occurred. In one study the participants described their most recent fall more than 12 months after it occurred.\(^55\)
Differences have been reported in the dynamic balance between PwMS who fall and non-fallers. Fallers walked slower and with more caution compared to non-fallers. They also had a greater variation in step length, and the foot was kept closer to the ground during the swing phase, compared to non-fallers and healthy controls.61

A systematic review62 including eight articles identified several risk factors for falls in PwMS: activities of daily living (ADL), balance, cognition, continence, dual task, fatigued, fear of falling, gait, mobility, mobility aid (walking aid or wheelchair), motor function, MS status/disease severity, MS type (RRMS, SPMS, PPMS), proprioception, spasticity, strength and visual issues. Meta-analysis was feasible on four of the risk factors and demonstrated an increase in fall risk associated with impairments of balance and cognition, progressive MS and the use of mobility aids (walking aids or wheelchair).62

Fall risk factors can be classified as either intrinsic or extrinsic. Reported identified intrinsic fall risk factors for PwMS are, for example, lower extremity malfunction,55 limited walking abilities, reduced muscular endurance, divided attention,49 not paying attention,58 fatigue49,58 and heat sensitivity.49 Examples of identified extrinsic fall risk factors are environmental factors,49 such as slippery or uneven surfaces, or malfunction or non-use of walking aids.55

Falls have been reported to lead to injuries58,60 PwMS also have an increased risk for fractures compared to healthy controls.63 Furthermore, falls can lead to fear of falling, which is an intrinsic fall risk factor. Fear of falling is a lasting concern about falls, which can lead to restriction or avoidance of activities that the individual is still capable of managing and is reported in over 60% of PwMS.64 Women, individuals who have reported having fallen during the last six months and individuals who use a walking aid are more likely to report fear of falling.64 Fear of falling has been reported to be associated with recurrent falls,65 as well as with EDSS score.66 More than 80% of the individuals expressing fear of falling experience curtailment of activity.64 Such activity curtailment can in turn lead to greater fall risk, creating a negative spiral. Use of a walking aid was correlated with a greater likelihood of reporting activity curtailment.64 Fear of falling has been reported to have an association with postural control in PwMS.66,67
Near falls in MS
A near fall is when a person is about to fall, but manages to restore balance and thus avoid falling. It is defined as: ‘an occasion on which an individual felt that they were about to fall but did not actually fall’.68 Near falls occur more frequently than actual falls and are reported in over 80% of PwMS.60 Correlation has been established between near falls and falls.59 However, no study has yet to my knowledge used near falls as an outcome measure in an intervention study. Including near falls as an outcome measure would give additional information on how the participants’ balance appears in everyday life.

Use of walking aids in MS
One strategy for maintaining active in everyday life despite impaired balance is to use a walking aid. Using a walking aid can be seen as a marker of MS disease progression and thus a decreased level of function. Walking aids are frequently used by PwMS; up to 60% have reported having at least one walking aid, and the majority of them have more than one.69 However, having a prescribed walking aid does not mean that the walking aid is being used regularly,69 which could be considered as a non-use of the aid. A resistance towards using walking aids has been expressed in nearly 50% of PwMS who use one.70 Around half of all walking aid prescriptions were encouraged and initiated by physiotherapists.70 The result showing resistance towards using a walking aid70 could mean that people who need to have a walking aid prescribed refrain from using the described aid. When receiving a walking aid, it is important to use it correctly.

Walking aids require dual tasking,71 a facility previously described as impaired in PwMS.49-51 Whether use of a walking aid is a help or a hindrance is unclear. A systematic review and a meta-analysis have identified the use of a walking aid as a risk factor for falls,62, 72 but PwMS have highlighted the use of walking aid as a factor preventing falls.49
Exercise to improve balance and reduce falls

Decades ago, exercise in PwMS was believed to aggravate the disease or cause injuries. Today, evidence shows that exercise should be a mainstay of treatment for PwMS. Physiotherapists tailor interventions to reduce or manage symptoms and maintain or improve function. They also supply suitable assistive technology such as walking aids as well as educating and informing both individuals and their next of kin and promoting overall health. Physiotherapists strive to assist each individual to achieve the highest possible level of independence. Physiotherapy in PwMS should preferably be individualized and adjusted to improve function for each individual. It is also important to promote physical activity among PwMS, since they are more physically inactive than healthy controls. A sedentary lifestyle has been reported. MS-related symptoms may worsen due to low levels of physical activity. Coaching PwMS to find a suitable exercise at the right level is within the field of physiotherapists’ expertise.

There is some evidence indicating that balance can be improved by exercise in PwMS, and that frequency of falls thus can be reduced. However, the results in studies regarding balance exercise are inconclusive.

Balance exercise for people with mild to moderate MS

Since balance is complex, there are several ways to exercise for balance. Various components are involved in the act to achieve balance, and therefore, different types of exercise have been evaluated in the balance exercise interventions. (See Table 1). Studies on combined motor and sensory training, visuo-proprioceptive feedback training, vestibular rehabilitation, core stability training and dual-task training have shown promising results in improving balance and possibly reducing falls. The balance exercise studies have different duration of the intervention, ranging from 240 to 1440 minutes.
<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Design: type of exercise</th>
<th>Duration of exercise</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cattaneo et al.</td>
<td>44 PwMS</td>
<td>RCT:</td>
<td>10–12 times, each session lasting 45 minutes</td>
<td>Improved balance and reduced numbers of falls for the balance exercise groups, with an advantage for combined training</td>
</tr>
<tr>
<td>Prosperini et al.</td>
<td>40 PwMS</td>
<td>Cross-over study:</td>
<td>6 weeks, twice weekly, each session lasting 45 minutes</td>
<td>Improved balance and reduced falls</td>
</tr>
<tr>
<td>Hebert et al.</td>
<td>38 PwMS</td>
<td>RCT:</td>
<td>6 weeks, twice weekly, each session lasting 55 minutes</td>
<td>Improved upright postural control in favour of the vestibular rehabilitation group</td>
</tr>
<tr>
<td>Ozgen et al.</td>
<td>44 PwMS</td>
<td>RCT:</td>
<td>8 weeks, once weekly, each session lasting 30–45 minutes</td>
<td>Improved static and dynamic balance</td>
</tr>
<tr>
<td>Freeman et al.</td>
<td>8 ambulatory PwMS</td>
<td>Case series: Core stability exercise</td>
<td>8 weeks, twice weekly + daily home exercise programme</td>
<td>Improved balance and mobility skills</td>
</tr>
<tr>
<td>Sosnoff et al.</td>
<td>14 PwMS (EDSS mean 2.1)</td>
<td>RCT:</td>
<td>12 weeks, twice weekly, each session lasting 60 minutes</td>
<td>Trend in improvement of dual-task gait speed and visuospatial memory for the dual-task group</td>
</tr>
<tr>
<td>Monjezi et al.</td>
<td>42 PwMS (EDSS mean 2.8)</td>
<td>RCT:</td>
<td>4 weeks, thrice weekly, each session lasting 45 minutes</td>
<td>No differences between the groups</td>
</tr>
</tbody>
</table>
Freeman et al.\textsuperscript{86} added a home exercise programme, which participants were encouraged to perform daily. The adherence to the home exercise programme was excellent, 80.5%.\textsuperscript{86} Adding home exercises to an intervention can be a way to achieve a habit to keep exercising after the intervention period is ended. Hoang et al.\textsuperscript{89} and Sosnoff et al.\textsuperscript{90} have evaluated home-based exercise exclusively and have reported that a 12-week home-based exercise programme for people with mild to moderate MS is a safe and effective way to improve balance and reduce the risk of falls.\textsuperscript{89, 90}

**CoDuSe balance exercise**

Based on the work of Freeman et al.,\textsuperscript{86} Cattaneo et al.,\textsuperscript{82} Prosperini et al.\textsuperscript{83} and Hebert et al.,\textsuperscript{84} and in a collaboration with a clinically based physiotherapist working with neurological rehabilitation, a group-based balance exercise programme was developed.\textsuperscript{91} The aim of the balance exercise programme was to target different factors believed to be of importance in maintaining balance during activities, identified as impaired in PwMS, namely, core stability (Co), dual tasking (Du), and sensory strategies (Se), with the purpose of enhancing balance and reducing numbers of falls. The exercise concept was called CoDuSe. It was evaluated in a randomized controlled trial (RCT) including 87 people with mild to moderate MS who were able to walk at least 100 metres and to get up from the floor with minor support, but who were unable to maintain a tandem stance heel–toe with arms alongside the body for 30 seconds. A waiting-list design was used where the participants were randomized to either an early or late start group. The participants exercised 60 minutes twice weekly for seven weeks. The exercise programme started with 20 minutes of core stability exercises, followed by 15–20 minutes of dual-task exercises and 15–20 minutes of exercises challenging sensory strategies. The participants were encouraged to maintain focus on core stability during the exercises targeting dual task and sensory strategies as well. Each session ended with five minutes of relaxation. As a result, there were statistically significant differences between the intervention and the control groups in change in the primary outcome measure Berg Balance Scale (BBS) and in the secondary measures postural sway with eyes open, functional gait assessment (FGA), MS Walking Scale (MSWS), and Activity-specific Balance Confidence (ABC) Scale in favour of the intervention group. Hence, the CoDuSe balance exercise increased dynamic balance for PwMS with mild to moderate MS.\textsuperscript{91} The intervention also reduced numbers of falls and fallers. Seven weeks before the intervention the participants in the late start group fell 166 times, and 53% were classified as fallers. Seven weeks
after the intervention the falls in the same group were reduced to 43 falls, and 31% were classified as fallers.\textsuperscript{92}

In this thesis the group-based balance exercise programme will be referred to as the CoDuSe balance exercise.

**Balance exercise for people with moderate to severe disability**

Previous research targeting balance and falls in PwMS has mostly included people with mild to moderate MS. However, recent research has reported that it is of great importance to develop exercise interventions suitable for people with more advanced MS, since the consequences of disease progression on overall disability were more prominent in individuals with moderate/severe MS compared to those with mild MS.\textsuperscript{93}

A systematic review of the effects of exercise training in people with severe disability due to MS has been conducted.\textsuperscript{94} The authors included 19 articles with different types of exercise (i.e. aerobic exercise training, n = 3; resistance exercise training n = 2; body weight support treadmill training, n = 8; total body recumbent stepper training, n = 1, and electrical stimulation assisted cycling; n = 5), but none of them evaluated specific balance exercise.\textsuperscript{94}

However, a few studies have evaluated the effect of balance exercise in people with moderate to severe disability due to MS. Van der Linden et al.\textsuperscript{95} conducted a group-based core stability exercise programme, Pilates. Twelve PwMS who used wheelchairs were recruited to a total of 18 hours of supervised, group-based Pilates classes, for 12 weeks. They reported improved sitting balance after the end of the intervention.\textsuperscript{95}

Built on the results from the case series evaluating core stability exercise,\textsuperscript{86} a multicentre RCT was conducted.\textsuperscript{96} This was a three-armed trial which compared core stability exercise (referred to as Pilates) to standard exercise and relaxation sessions (controls). The participants in the Pilates and standard exercise groups attended one half-hour session a week for 12 weeks, with the addition of a 15-minute individualized home exercise programme. The controls attended three face-to-face relaxation sessions of 60 minutes duration, at four-week intervals. One hundred participants were included, having an EDSS score between 4.0 and 6.5. The results showed that the
Pilates exercise did not significantly improve walking capacity or perceived balance confidence compared to controls.96

**Why qualitative evaluation of exercise is needed**

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.97-99 Since maintaining balance is a complex task, requiring several different skills in different situations, it is important to know whether the balance exercise improves balance in situations that are hard to handle. Having knowledge of how the participants perceive the effects of an intervention in everyday life is important, since it’s not known how well the possible exercise benefits transfer from the exercise room to real life.

There are previous qualitative evaluations of different types of exercise interventions for PwMS.100 However, to our knowledge, only a few studies have specifically evaluated interventions targeting balance exercise, using both quantitative and qualitative approaches.95, 101, 102 Two of them evaluated exergaming,101, 102 and one Pilates for wheelchair users.95 In the interviews participants reported that the balance exercise intervention was feasible.95, 101, 102 The two studies evaluating exergaming reported how the balance exercise positively affected balance and walking in everyday life due to increased body control.101, 102 Independence102 as well as increased confidence in everyday life was reported.95

**Next of kin**

A family is a group of people who are related to each other either by consanguinity (by recognized birth), affinity (by marriage or other relationship) or co-residence. Families work as a unit towards homeostasis, or stability in patterns of functioning.103 Yet, within the family, individual processes of change and development occur. The need for stability within the family is possibly the highest when exposed to stress.103 Being diagnosed with MS, or having a relapse, can be considered a crisis.104

Since MS onset often is in the midst of life, PwMS often share life with a family at the time. MS affects the whole family, both practically and emotionally,104-106 and the next of kin are also challenged to adapt to this new
Next of kin have reported in a large study that their personal income as well as work life and employment could be negatively affected due to the fact that their partner has MS. The next of kin also described decreased personal freedom, since they no longer can do what they were used to doing before, owing to a greater responsibility in the family situation. They have also described a constant concern about their family member with MS, a heightened awareness that may lead to restriction in choice of activities and life choices. Next of kin have also described how they feel uncertainties about the future, since the prognosis of the disease is uncertain, something that creates feelings of hopelessness. Hence, MS is a family matter. Given the fact that next of kin to PwMS also are affected by the disease, it is important to focus on the needs of the next of kin as well as the needs of the PwMS.

Knowledge is limited on how the lives of the next of kin to PwMS are affected by the fact that their family member occasionally falls. A previous study of nine individuals with the diagnosis intellectual disability together with their family members reported that the family members could help prevent falls by adapting the activities performed and the environment in which they lived. The family members also described how it was impossible to be constantly physically present to give physical support to prevent falls. Not being able to be constantly present could lead to feelings of anxiety and guilt connected to the impossible task of keeping their family member from falling. It has emerged as an incidental finding in a previous Swedish study that next of kin to PwMS are affected by the risk of a family member falling.

In this thesis the term next of kin will be used to refer to people who reside with PwMS.
Rationale

It is important to understand in which situations falls occur in PwMS and how to tailor interventions and protective measures. Moreover, information on whether the walking aids used are helpful or hindering for PwMS is crucial in MS care. Most previous studies that describe the circumstances regarding falls in MS have collected data on falls after long period of times or by using falls diaries, first reported 12 months after the falls occurred. Interviews add a deeper understanding of when and why the falls occurred and offer the possibility of asking follow-up questions to get an overall picture. A long period of time from the event to follow-up can induce recall bias. Information collected soon after experiencing a fall is therefore of interest to properly describe the circumstances regarding the fall. Such knowledge can allow healthcare personal to individualize fall preventive strategies.

Given the fact that balance can be improved and fall frequency reduced with exercise for people with mild MS, it is of interest to examine whether similar effects can also be achieved in moderate to more severe stages of the disease, especially since impaired balance and falls are more frequent in these populations. Also, it is not certain whether a potential change in a clinical outcome measure can be effectively transferred to everyday life for the participant. To provide PwMS with fall-preventing strategies is an important task for physiotherapists, since falls have been reported to lead to injuries. This thesis will contribute to the evidence on whether or not people with moderate to severe MS also experience benefits from exercising with the CoDuSe balance exercise. They will provide information on whether or not the participants themselves found the balance exercise to be useful for them in everyday life.

It is known that falls due to MS affect the person who falls. It is also known that MS affect the life of their next of kin. However, it is not known whether the fact that PwMS fall also affects the everyday lives of their next of kin, and if it does, in what way. Increased knowledge of the perspective of the next of kin may enable carers in the healthcare system to provide appropriate support. It is likely that next of kin play an especially important role in the lives of PwMS, due to the disease’s progressive and multidimensional symptoms. This study will contribute to a greater societal understanding of the next of kin’s situation as well that of PwMS.
**Aims**

The overall aim of this thesis was to gain enhanced knowledge by investigating when and why people with MS fall and how these falls possibly affect their next of kin, and also to evaluate the effects and perceptions of participating in a specific balance exercise.

The studies’ specific aims were as follows:

I. To describe falls and the perceived causes, experienced by people with multiple sclerosis shortly after falling.

II. To evaluate the effects of the CoDuSe exercise concept for PwMS with EDSS score 4.0–7.5, during 7 weeks of twice-weekly, physiotherapist-led 60-minute sessions in groups of two to five people with the addition of an individually designed home exercise programme.

III. To describe the experience and perceived effects on everyday life for people with MS after participating in the CoDuSe programme.

IV. To describe how everyday life is experienced by next of kin sharing residence with a person who falls due to MS.
Methods

Design
The data in this thesis were gathered using four separate data collections during 2014 and 2015. Telephone interviews were conducted with PwMS who had recently fallen (study I). A balance exercise intervention was conducted where both quantitative and qualitative data were used to evaluate the effects (studies II and III). Face-to-face interviews were also conducted with next of kin to PwMS who were frequent fallers (study IV). All studies were multi-centre studies, eight in total; nine centres participated: five hospitals (the Department of Physiotherapy at Örebro University Hospital, Rehab Clinic at Västerås Hospital, Physiotherapy Clinic at Nyköping Hospital, Physio Therapy Special Care at Gävle Hospital and NeuroRehab at Mälarpalatset in Eskilstuna) and four primary healthcare centres (Brickegårdens Primary Health Care Centre in Karlskoga/Rehab Unit Karlskoga Hospital, Physiotherapy Primary Health Care Centre in Linköping, Physiotherapy Primary Health Care Center in Motala and Rehab Unit Central Hospital Karlstad), altogether representing six county councils/regions. Table 2 presents an overview of the four studies.

Table 2. Overview of the study designs and methods

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample</th>
<th>Data collection</th>
<th>Main data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Qualitative descriptive</td>
<td>67 PwMS</td>
<td>Telephone interviews</td>
<td>Content analysis</td>
</tr>
<tr>
<td>II</td>
<td>Randomized controlled pilot trial</td>
<td>51 PwMS</td>
<td>Pre- and post-intervention and follow-up measures</td>
<td>Mixed covariance pattern model</td>
</tr>
<tr>
<td>III</td>
<td>Qualitative descriptive</td>
<td>27 PwMS</td>
<td>Face-to-face interviews</td>
<td>Content analysis</td>
</tr>
<tr>
<td>IV</td>
<td>Qualitative descriptive</td>
<td>20 next of kin</td>
<td>Face-to-face interviews</td>
<td>Content analysis</td>
</tr>
</tbody>
</table>
Study populations
The participants were recruited from seven or eight different centres for each separate study; see Figure 6. In each centre, clinical physiotherapists were in charge of the recruitment process for the studies.

Figure 6. Overview of the cities with centres participating in the studies.

For inclusion in studies I, II and III, participants had to have MS diagnosed according to the McDonald criteria. For inclusion in study I, in addition to being diagnosed with MS, the informants had to report at least one fall during the previous three-month
period and use a walking aid (intermittently or continuously). Potential informants were identified by physiotherapists responsible for recruitment at each centre. Additional information was given to the informants by contact with the study leader (doctoral student Anna Carling, A.C.). Informed consent for study participation was obtained. In order to include a broad variety of experiences around the falls and make it possible to quantitatively rank the categories, we strived to acquire descriptions of at least 100 falls. The informants were enrolled consecutively. In total, 78 individuals were identified as eligible according to the inclusion criteria and asked to participate. When 67 informants had agreed to participate, the recruitment process ended, since we calculated that at least 30% of the informants would fall more than once during the study period, based on the international meta-analysis that reported that 37% of fallers are frequent fallers.

Specific inclusion criteria in studies II and III, besides being diagnosed with MS, were having the ability to walk 20 metres, but not exceeding 200 m (with or without a walking aid) and ability to transfer between a wheelchair and a plinth (in order to be able to participate in the intervention). Exclusion criteria were (1) cognitive symptoms making it difficult to understand study information, follow instructions or fill in rating scales; (2) having sought medical care related to impaired walking during the past three months so as not be in a current or recent relapse; (3) having participated in balance exercise administered by health care personnel during the past 30 days; and (4) having started or changed medication with 4-aminopyridine during the past 30 days (a medication promoted as improving walking). Eligible participants were identified by responsible physiotherapists at each centre, using personal knowledge and/or access to the Swedish Neuro Register (with permission from the registry holder). In total, 102 individuals were identified and invited to participate, of whom 51 were included (see Figure 7). At the end of the intervention period we strived to interview 20 participants; a purposeful sample of 27 participants was asked to take part in an interview, and all of them accepted participation. To achieve variety in sex, age, centre and disease burden, a purposeful sample was performed.

Eligible informants for study IV were adults (>18 years) who resided with PwMS who had experienced and reported a fall in study I. We strived to conduct 20 interviews. Twenty-two of the participants in study I were asked for permission to contact their next of kin and invite them to participate in
study IV, using consecutive sampling. Contact information for the 22 next of kin was retrieved from the PwMS, and 20 accepted participation.

**Procedure and data collection**

**Fall situations in PwMS, study I**

Demographic data were collected via a study-specific questionnaire sent by mail, including the patient-administered EDSS\textsuperscript{35} in which the disease burden is self-rated. The patient-administered EDSS was interpreted by an experienced neurologist to determine an EDSS score in order to describe the disease burden.

The informants were instructed to contact the study leader (A.C.) by e-mail, text message or telephone immediately after having experienced a fall. A fall was defined as ‘an unexpected event in which participants come to rest on the ground, floor, or lower level’.\textsuperscript{56} The interviews were either conducted directly at contact, often the same day as the fall, or scheduled shortly thereafter (0–10 days). Each informant could be interviewed a maximum of three times. Every two weeks, reminders to get in touch if they fell were sent by a text message.

An interview guide was constructed with four content areas: (1) description of the fall, (2) regular use of a walking aid, (3) the process when the walking aid was prescribed, and (4) the role of the walking aid in the fall situation reported. The first question asked was standardized: ‘Can you tell me what happened the last time you fell?’ Follow-up questions were asked for deeper understanding. At the end of each interview, the informants were encouraged to tell the interviewer anything else they wanted to talk about related to the fall that had not been covered by the interview questions. All interviews were conducted by A.C. and audio recorded with permission and transcribed verbatim by a research secretary or by A.C. The first interview with each person reporting a fall included collection of background information and took between 8 and 54 minutes (mean 19 minutes). The second and third interview took between 2 and 22 minutes.

**The CoDuSe balance exercise, studies II and III**

A multi-centre, randomized, controlled pilot study was conducted, across seven centres in five different County Council/Regions in Sweden.
Using a waiting list design, participants were randomly allocated to intervention with either early or late start, where the late start group served as control group. The participants allocated to late start were urged to maintain their present physical activity levels.

An external statistician conducted a computerized random allocation sequence with varied block sizes (2–6). Concealed allocation was achieved using sealed envelopes, which were opened right after baseline measure by the physiotherapist in charge at each site. Blinding of raters was accomplished with the raters travelling to different centres, unaware of allocation. Each participant was always measured by the same rater during all occasions.

Since the late start group served as control group, the randomized control ended after the second measurement occasion, at week eight. However, quantitative data were collected at three (early start group) or four (late start group) different measurement occasions: before the intervention (week 0), after 8 weeks, after 16 weeks and after 24 weeks, in order to obtain follow-up data (see Figure 7). A.C. acted as rater at four of the centres (Västerås, Eskilstuna, Nyköping and Linköping) and as a treating physiotherapist at one (Örebro).
Figure 7. Flow chart of studies II and III.

CoDuSe balance exercise
As described, the exercises were initially customized to fit PwMS with a mild to moderate disability. To fit the disability level of the sample in the present study, an extensive interactive process was performed, including all participating physiotherapists from all participating centres. During this interactive process, which lasted for one day, the physiotherapists discussed and received practical training in suitable exercises and the progression of them to ensure consistency. After the discussions a manual including the
suitable exercises was created and further discussed in the group until consensus was reached.

The 60-minute group-based balance exercise was given in small groups (two to five people) twice weekly during a seven-week period with at least one physiotherapist present. The first 30 minutes were primarily focused on core stability exercise, that is, controlled leg movements; see Table 3 and Figure 8 for examples. The participants were encouraged to maintain focus on core stability while performing the remaining exercises, which included dual tasking and sensory strategies, such as carrying something while walking or walking on an uneven surface (Table 3).
Table 3. Examples of exercises and their progression

<table>
<thead>
<tr>
<th>Position</th>
<th>Exercise</th>
<th>Progression</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Core stability</strong></td>
<td>Lie on your back with knees bent, feet flat on the floor</td>
<td>Slow movements of the arms</td>
</tr>
<tr>
<td></td>
<td>Lie on your back with knees bent, feet flat on the floor</td>
<td>Lift one foot off the floor and bring the knee over the hip so that the hip and knee are flexed to 90°</td>
</tr>
<tr>
<td></td>
<td>4-point kneeling</td>
<td>Slide one foot in a straight line away from the body, then slide foot back to starting position</td>
</tr>
<tr>
<td></td>
<td>Sitting position on a Bobath ball</td>
<td>Extend one leg</td>
</tr>
<tr>
<td><strong>Dual task, maintaining core stability</strong></td>
<td>Sitting position</td>
<td>Move an item from one side to the other</td>
</tr>
<tr>
<td></td>
<td>From a sitting to a standing position</td>
<td>Rising up carrying a tray</td>
</tr>
<tr>
<td><strong>Sensory strategies, maintaining core stability</strong></td>
<td>Sitting position</td>
<td>Sitting on a soft surface</td>
</tr>
<tr>
<td></td>
<td>Standing</td>
<td>Standing on a moving surface</td>
</tr>
</tbody>
</table>

Throughout the intervention period, the participants were encouraged and instructed by the physiotherapist to progress to more challenging exercises when suitable.

In addition, they were given an individually tailored home exercise programme with two to five exercises. Progression of the exercises was continuously adjusted by the physiotherapists.
Study II
Four physiotherapists were responsible for the testing procedure and blinded to which group the participants were randomized to. Each participant was always measured by the same physiotherapist. Prior to the study start, the data-collecting physiotherapists were given a half day of training to minimize systematic differences in rating and measuring the participants’ performance. An optional walking aid was allowed for the walking tests. Each participant’s chosen walking aid was then used consistently by the participant at each assessment.

Outcome measures
The primary outcome measure was the Berg Balance Scale (BBS),\textsuperscript{113} an outcome that measures static and dynamic balance using 14 items rated from 0 to 4, giving a maximum score of 56. A higher score indicates better balance. The BBS is a valid and reliable test for PwMS.\textsuperscript{114-116}

Secondary outcome measures were as follows:
The Fatigue Scale for Motor and Cognitive Function (FSMC),\textsuperscript{117} is divided into two subscales and measures motor and cognitive fatigue. Each scale contains 10 items, and the 20 items in total have a maximum score of 100. A high score indicates severe fatigue. It has a high internal consistency as well as test-retest reliability and discriminates between PwMS and healthy controls.\textsuperscript{117}

The Trunk Impairment Scale (TIS)\textsuperscript{118} measures trunk stability while sitting, using three subcategories (static, dynamic and coordination) and has a maximum total score of 23. A high score indicates stability. It is valid for PwMS.\textsuperscript{119}

The timed sit to stand (TstS) test measures time while performing five repeated transfers from sitting to standing.\textsuperscript{120} The test was slightly modified for safety reasons; instead of crossing arms over the chest as the original test procedure suggests, hand support was allowed. The test is valid for people with moderate MS.\textsuperscript{121}

Postural sway in standing without shoes was measured using a sway meter,\textsuperscript{122} where an area from dash of the pen occurs. Two different conditions were tested, with eyes open and with eyes closed for 30 seconds.\textsuperscript{122}

The Falls Efficacy Scale–International (FES-I) is a self-rating scale that measures the concerns about falls in 16 everyday life situations. A high score indicates considerable concern about falls. It is a valid and reliable self-rating scale for PwMS (maximum score = 64).\textsuperscript{123, 124}

The 12-item Multiple Sclerosis Walking Scale (MSWS) measures the perceived walking ability, where the participants rate the extent to which MS has limited their walking ability during the past two weeks. The maximum score is 100, where a high score indicates higher limitation. The test is valid and has a high internal consistency as well as test-retest reliability for PwMS.\textsuperscript{125}

Timed up and go (TUG) measures basic mobility.\textsuperscript{126} Time is registered from when the person arises, walks 3 metres, turns around, walks back and sits down again. A test trial was allowed, and one
attempt was registered.\textsuperscript{127} TUG is a valid and reliable test, with high test-retest reliability for PwMS.\textsuperscript{114, 116}

- The 10-metre walk test (10WT)\textsuperscript{128} measures walking speed. Time to walk 10 metres, quickly but safely, starting from a standing-still position was registered. Two attempts were performed and the mean value was used in further calculations. The test has high inter-rater and test-retest reliability for PwMS.\textsuperscript{129}

- The 2-minute walk test (2MWT)\textsuperscript{130} measures walking endurance. The test was conducted using a 15-metre pathway in a quiet corridor. Walking speed during two minutes and metres walked during that time both have a discriminatory property for degree of MS severity.\textsuperscript{131}

Clinically administered and patient-reported outcomes were always performed in a standardized order: FSMC, TIS, TstS, postural sway, BBS, FES-I, MSWS, TUG, 10WT and 2MWT.

Disease burden was measured at the first test occasion (week 0), using the patient-administered EDSS.\textsuperscript{35} The ratings were interpreted by an experienced neurologist to determine a current EDSS for each participant, to enable description of the study sample.

To describe the participants’ cognitive functioning, the recommended outcome measure Symbol Digits Modalities Test (SDMT) was used at the second test occasion (week 8).\textsuperscript{132, 133} The test measures information processing speed and episodic memory.

Falls and near falls were prospectively reported daily from baseline to follow-up using a diary. Weekly reminders to fill in the diary were given by the physiotherapist after each session and by text message from the study leader. The diary also contained information regarding adherence to the home exercises. The diaries were collected by the physiotherapist responsible for the intervention or the rater at each centre during measurement occasions, or posted to the study leader in a pre-paid addressed envelope.

To detect a three-point reduction in BBS, with a two-sided 5% significance
level and a power of 80%, a sample size of 45 was required. We aimed to enrol at least 50 participants to account for possible dropouts.

Study III
The participants were first invited via letter and later contacted by telephone by A.C. to schedule an interview at a location chosen by the participant. The majority chose their own homes, three preferred to be interviewed at the local hospital and one chose a local café. The interviews were conducted 2–10 weeks after the whole intervention period finished (see Figure 7). We strived to interview at least 20 participants.

A semi-structured interview guide was developed by discussion in the research group, and was further discussed with experienced physiotherapists who acted as treating physiotherapists during the intervention. The initial question was always: ‘You participated in the CoDuSe balance exercise programme; can you tell me about your experience?’ Follow-up questions from the interview guide were then asked to get information on both the experience of the exercise intervention as well as their perceived effects of the exercise on their everyday life. A.C. conducted all interviews, which lasted 10–37 minutes (mean 22 minutes) and were recorded with permission. They were later transcribed verbatim by two experienced research secretaries.

Next of kin, study IV
Face-to-face interviews were conducted by A.C. between November 2014 and June 2015 and took place in the participant’s home (n = 12), at a local hospital (n = 6), at a local restaurant (n = 1) or at the participant’s workplace (n = 1); the location was chosen by the next of kin. A semi-structured interview guide was used with the standardized opening question: ‘Your next of kin sometimes falls; please tell me how that affects you’. Follow-up questions were asked in order to capture information about feelings, actions and customizations in different areas of life. The interview guide was created through discussions in the research group, and later on tested on a next of kin to a person who had recently fallen (not due to MS). The participants sometimes talked about the situation regarding MS as a whole, since falling is only a part of it. However, they were always led back to focusing on how the falls affected them. The interviews were recorded with permission from the participants and took between 27 and 51 minutes (mean 38 minutes) and were transcribed verbatim by experienced research secretaries.
Data analysis

Quantitative data analysis, study II
The between-group comparisons were performed using intention-to-treat analyses with a mixed covariance pattern model for repeated measures data. An unstructured covariance matrix was used with adjustment for sex, age and MS subtype at baseline. This analysis takes care of missing data in an optimal way. Effect size (ES) for change between two groups was calculated (mean difference/pooled standard deviation (SD)) and for change within groups (mean differences/SD for the differences). The overall trend for number of falls and near falls in the late-start group was estimated using the slope from a linear regression within each participant. The overall trend was tested with the Wilcoxon signed-rank test over the participants. For comparison over time, the Wilcoxon signed-rank test was used for continuous variables. For the statistical analyses SAS System version 9.4 (SAS Institute, Cary, NC, USA) and SPSS version 22.0 (IBM Corp., Armonk, NY, USA) were used.

Qualitative data analysis, studies I, III and IV
All qualitative data in the studies (I, III, IV) were analysed with qualitative content analysis, however with different depth and approaches. The choices of analytical method were made based on the aim and content of the interviews. The interviews concerning the falls (study I) were analysed using a manifest analysis, while the interviews concerning the experience and perceived effects of the exercise intervention (study III) had a latent approach, but were still kept close to the text. The interviews with the next of kin (study IV) were latently analysed interviews.

The initial steps in all three studies were the same. The recordings were listened to and compared to the written transcripts by A.C., in order to correct any eventual errors or ambiguities. The transcripts were then read several times in their entirety to get an overall view of the material, by A.C. and the co-authors. The interviews were all condensed on the basis of the aim by A.C. After these steps, the analyses differ.

In the interviews concerning falls (study I), first, a manifest analysis was performed in which the overall activity in the fall situation was analysed and qualitatively ranked, as described by Weber. This analysis was kept close to the text. Later, when analysing the perceived possible causes for the
falls, a more latent approach was used, as described by Graneheim and Lundman. The codes were grouped together into categories. During this process, codes were moved back and forth between categories. To attain homogeneity within the categories, the categories were organized to be exhaustive and mutually exclusive.

In the interviews concerning the experience and perceived effects of the exercise intervention (study III), the content analysis was performed as described by Elo and Kyngäs. In the preparation phase the whole interviews were selected as the unit of analysis. Only the manifest content, that is the text, was analysed. After preparing the data previously explained, the organization of the data continued. Open coding based on the purpose was written down and fused together, creating a coding sheet. The codes were then grouped together in to subcategories, in order to describe the similarities and differences in the participants’ statements. The subcategories were grouped together as categories, and the categories were abstracted to generate a general description using an overall theme for the categories. There was a constant moving back and forth in the process. In the reporting, the results are the described content of the categories, and the content of the categories is described through subcategories.

In the interviews with the next of kin, study IV, a latent content analysis was conducted. The interviews were extracted on the basis of the aim and brought together into one text, which constituted the unit of analysis. This text was then divided into meaning units related to the aim. The meaning units were also condensed. The whole context was considered when condensing and labelling the meaning units with codes. The codes were compared and grouped together into nine categories based on differences and similarities into nine categories, constituting the manifest content. This was an extensive process moving back and forth through the steps of the analysis. A latent analysis of the categories was then conducted, and grouped together into three themes. An abstraction of the three themes resulted in an overall theme, which covers the whole material.

In all three qualitative studies the analysis was primarily conducted by A.C., but every step in the process was continuously discussed with the co-authors until consensus was reached. Authentic citations from various interviews were selected in all studies to illustrate, reflect and support the results as well as to strengthen the trustworthiness. All interviews were carried out in
Swedish, and the citations were translated into English by a professional translator. As help in the analysis, versions 10 and 11 of the N-Vivo software package (QSR International, Victoria, Australia) were used during the analytical processes.
Ethical considerations

All studies were conducted following the Helsinki Declaration of ethical principles for medical research involving human subjects. All studies were ethically approved by the Regional Ethical Review Board in Uppsala, Sweden (ref 2014/302 date of approval 2014-08-13 for studies I, II and IV, and additional application ref 2014/302/1 date of approval 2015-02-10 for study III).

Informed written consents were mandatory for all participants in all studies. The participation was voluntarily and consent could be withdrawn at any time. It is possible that, by interviewing or evaluating them by outcome measures, we could make the participants aware of their possible problems with balance and falls. An increased attention to the problems could lead to increased awareness and thoughts about their potential shortcomings.

By using a waiting-list design in the balance exercise, studies II and III, all participants were able to take part in the exercise at some point. Participants were motivated to exercise, and it is therefore ethical to offer all of them the possibility. However, the participants might have felt a great need for the exercise ‘right now’ and not in two months. Intervention was randomized without making individual assessments as to when exercise would be most suitable. Also, since this was a study performed in clinical practice, no other balance group exercise was offered to this group of people during that time. PwMS not participating in the study may have missed the opportunity to practice balance exercise in groups, possibly receiving physiotherapy individually instead.

When participating in a balance exercise intervention where the balance is challenging, during both exercise and measurement, adverse events are possible. This demands experienced physiotherapists both when measuring balance as well as when leading the balance exercise. To provide safety during the group exercises, as the participants in studies II and III did have moderate to severe MS, the sizes of the groups were smaller than those in a previous study evaluating CoDuSe.

Recruitment of next of kin through other informants may also raise ethical considerations, as in study IV, and is worth mentioning. Informants were asked for permission to contact a cohabiting next of kin. The interviews
with the next of kin were deep and personal. It is possible that asking ques-
tions about one’s life situation might raise unprocessed feelings. It is also possible that the next of kin discussed questions and feelings with the PwMS or the rest of the family.

The participants in all studies were able to, at any time, contact the study leader if questions or uncertainties appeared. The participants in studies I, II and III all had a local contact within the health care system at each site in case something unexpected occurred. Participants in study IV could be referred to a suitable person within the health care system, if necessary.

Despite all possible ethical dilemmas, the benefits from participating in the studies were considered to outweigh the disadvantages.
Results

Fall situations in PwMS, study I

In total, 106 interviews were conducted, resulting in 115 unique fall situations. Of the 67 informants, 85% (n = 57) reported at least one fall, and 48% (n = 32) reported multiple falls. Some informants experienced multiple falls within a short period of time and could report more than one fall during an interview.

The informants had a moderate to severe disability (EDSS score 3.5–7.5; median 6.0), and most of the informants were females (73%). They were most likely using a walking aid, both indoors (70%) and outdoors (94%).

The content analysis resulted in two different categories: ‘Activities when falling’ represents the main activity performed when the fall occurred, and ‘Influencing factors’ are the factors that the informants themselves believed to have influenced the fall situation. Each category is constituted by three and six subcategories, respectively (see Figure 9).

Most frequently, the reported falls occurred indoors (78%), in the informants’ own homes. The falls occurred during performance of everyday activities. Despite the risk of falling, it was still considered important to continue activities rather than avoiding them. According to the informants, to do otherwise would have constrained their lives significantly. Most of the falls occurred while engaging in basic ADL (46%), such as transfers and personal hygiene. Second, most commonly the informants fell during instrumental ADL (38%), while performing household chores or preparing meals or when moving about within the community. The remaining falls (18%) occurred either during leisure activities such as horseback riding or during work hours.
Several different factors, individually or in combination, had induced falls because of a sudden loss of control. The factors described were both intrinsic (MS-related symptoms, fluctuating body functions, being distracted and losing body control) and extrinsic (challenging surrounding and involvement of walking aid). The intrinsic factors could all be related to having MS, and the impact on falls due to fluctuating symptoms within a day is a novel finding. Intrinsic factors can influence extrinsic factors, and vice versa, which impinge on the activities performed.
The fall situation as a whole appeared in commonly performed activities, influenced by both intrinsic and extrinsic factors, schematically demonstrated in Figure 9 and in the citation from informant 8:

It was early in the morning. Then of course I have the bathroom a ... So then I start walking, using the walker. It’s a little less than 10 metres to the bathroom. And when I have to get up and go to the bathroom. I’m in quite a hurry. So with the walker I get myself into the bathroom, feel the pressure, and with my last few steps I’m really rushing, and then I trip. I walk with the walker in front of me then, and I swing myself around it. Then I walk up to the toilet seat, but this time I didn’t do that – instead, I went straight for the toilet seat, because I was in such a rush, you know? And then I feel I really have to go, so I pull down my trousers and position myself, I position myself at the toilet, hovering over the toilet. And at the same time, I stumble on one of the wheels of the walker.

The walking aid was reported present in 35 (30%) of the fall situations, and was not used properly in 24 (21%) of the falls. The majority (72%) of the informants who reported a fall perceived that they never received any practice at all in how to use the walking aid, when the walking aid was prescribed. Some mentioned that they had received verbal information regarding how to use it and that practical adjustments were made to fit the user. Only four participants talked about taking part in a shorter practice (5–30 minutes) in use of the walking aid at the healthcare location.

**CoDuSe balance exercise, studies II and III**

In total, 51 participants were included in the CoDuSe balance exercise pilot RCT, and afterwards, 27 were interviewed. Dynamic balance, measured with BBS, was significantly different, and there was clinically relevant improvement (mean 3.65 points) in favour of the intervention group ($p = 0.015$). The perceived walking limitation measured with MSWS showed borderline significant improvement (mean 7.21 points), again in favour of the intervention group ($p = 0.051$). There were no significant between-group differences for the other objective outcome measures. See Table 4.
<table>
<thead>
<tr>
<th></th>
<th>Intervention group (n = 25)</th>
<th>Control group (n = 26)</th>
<th>Difference Intervention – control p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Change, mean (95% CI)</td>
<td>Change, mean (95% CI)</td>
<td>Change, mean (95% CI)</td>
</tr>
<tr>
<td></td>
<td>Effect size</td>
<td>Effect size</td>
<td>Effect size</td>
</tr>
<tr>
<td></td>
<td>p-value</td>
<td>p-value</td>
<td>p-value</td>
</tr>
<tr>
<td>Bergs Balance Scale</td>
<td>4.57 (2.47; 6.66)</td>
<td>0.92 (-1.08; 2.92)</td>
<td>3.65 (0.75; 6.54)</td>
</tr>
<tr>
<td>(0–56)</td>
<td>p &lt; .0001</td>
<td>p = 0.36</td>
<td>p = 0.015</td>
</tr>
<tr>
<td>Timed up and go,</td>
<td>-0.95 (-5.57; 3.68)</td>
<td>-5.35 (-9.75; -0.96)</td>
<td>4.41 (-1.97; 10.79)</td>
</tr>
<tr>
<td>seconds</td>
<td>p = 0.68</td>
<td>p = 0.018</td>
<td>p = 0.17</td>
</tr>
<tr>
<td></td>
<td>-0.23 (-5.57; 3.68)</td>
<td>3.01 (-1.64; 7.65)</td>
<td>-3.24 (-10.03; 3.65)</td>
</tr>
<tr>
<td></td>
<td>p = 0.93</td>
<td>1.30</td>
<td>p = 0.34</td>
</tr>
<tr>
<td>2-minute walk test,</td>
<td>0.33 (-2.81; 3.47)</td>
<td>0.09 (-2.82; 2.99)</td>
<td>0.24 (-4.03; 4.52)</td>
</tr>
<tr>
<td>minutes</td>
<td>0.21</td>
<td>0.06</td>
<td>0.17</td>
</tr>
<tr>
<td>Timed sit-to-stand test,</td>
<td>0.92 (-4.72; 6.56)</td>
<td>-0.57 (-5.86; 4.72)</td>
<td>1.49 (-6.24; 9.23)</td>
</tr>
<tr>
<td>seconds</td>
<td>0.33</td>
<td>-0.22</td>
<td>0.56</td>
</tr>
<tr>
<td></td>
<td>p = 0.83</td>
<td>p = 0.83</td>
<td>p = 0.70</td>
</tr>
<tr>
<td>Postural sway, eyes</td>
<td>21.57 (-737.84; 780.99)</td>
<td>-105.30 (-851.39; 640.79)</td>
<td>126.87 (-937.68; 1191.43)</td>
</tr>
<tr>
<td>open, area (mm²)</td>
<td>0.06</td>
<td>-0.28</td>
<td>0.35</td>
</tr>
<tr>
<td></td>
<td>p = 0.95</td>
<td>p = 0.95</td>
<td>p = 0.81</td>
</tr>
<tr>
<td>Postural sway, eyes</td>
<td>-501.85 (-1898.01; 894.32)</td>
<td>-861.65 (-2179.09; 455.79)</td>
<td>359.81 (-1560.05; 2279.66)</td>
</tr>
<tr>
<td>closed, area (mm²)</td>
<td>-0.73</td>
<td>-1.33</td>
<td>0.55</td>
</tr>
<tr>
<td></td>
<td>p = 0.47</td>
<td>p = 0.19</td>
<td>p = 0.71</td>
</tr>
<tr>
<td>Trunk Impairment Scale</td>
<td>1.02 (-0.31; 2.35)</td>
<td>-0.02 (-1.30; 1.26)</td>
<td>1.04 (-0.81; 2.88)</td>
</tr>
<tr>
<td>(0–23)</td>
<td>1.54</td>
<td>-0.03</td>
<td>1.63</td>
</tr>
<tr>
<td></td>
<td>p = 0.13</td>
<td>p = 0.97</td>
<td>p = 0.26</td>
</tr>
<tr>
<td>Falls Efficacy Scale</td>
<td>-0.32 (-3.79; 3.14)</td>
<td>1.34 (-1.99; 4.66)</td>
<td>-1.66 (-6.46; 3.14)</td>
</tr>
<tr>
<td>(16–64)</td>
<td>-0.19</td>
<td>0.81</td>
<td>-1.00</td>
</tr>
<tr>
<td></td>
<td>p = 0.85</td>
<td>p = 0.42</td>
<td>p = 0.49</td>
</tr>
<tr>
<td>MS Walking Scale</td>
<td>-6.65 (-11.88; -1.42)</td>
<td>0.56 (-4.45; 5.57)</td>
<td>-7.21 (-14.46; 0.03)</td>
</tr>
<tr>
<td>(0–100)</td>
<td>-2.56</td>
<td>0.22</td>
<td>-2.89</td>
</tr>
<tr>
<td></td>
<td>p = 0.014</td>
<td>p = 0.82</td>
<td>p = 0.051</td>
</tr>
<tr>
<td>Fatigue Scale for</td>
<td>-2.43 (-6.53; 1.67)</td>
<td>-0.98 (-4.92; 2.96)</td>
<td>-1.45 (-7.14; 4.24)</td>
</tr>
<tr>
<td>Motor and Cognitive</td>
<td>-1.19</td>
<td>-0.50</td>
<td>-0.74</td>
</tr>
<tr>
<td>Functions, total (0–100)</td>
<td>p = 0.24</td>
<td>p = 0.62</td>
<td>p = 0.61</td>
</tr>
<tr>
<td>Fatigue Scale for</td>
<td>-2.20 (-4.52; 0.13)</td>
<td>-0.61 (-2.84; 1.63)</td>
<td>-1.59 (-4.82; 1.64)</td>
</tr>
<tr>
<td>Motor and Cognitive</td>
<td>-1.90</td>
<td>-0.55</td>
<td>-1.43</td>
</tr>
<tr>
<td>Functions, motor (0–50)</td>
<td>p = 0.063</td>
<td>p = 0.59</td>
<td>p = 0.33</td>
</tr>
</tbody>
</table>
In the interviews, participants described the CoDuSe balance exercise as facilitating their everyday lives. They reported that taking part in the CoDuSe balance exercise provided a novel awareness of their core muscles and how to activate the muscles. The activation also became more automated in everyday life activities. Having this awareness and ability led to a feeling of control over the body as well as functions such as balance, strength and postural control, and consequently, an improved bodily confidence. The participants described how improved bodily confidence as well as enhanced control of the body facilitated making everyday life activities safe and easy to perform. This was believed to improve their mobility, make activities easier and reduce the numbers of falls. It was described as increasing their independence and participation. It made them feel less dependent on others and more confident. Moreover, walking aids were used to a lesser extent. For a schematic overview of the result of the analysis, including the overall theme, categories and subcategories, see Figure 10.

Figure 10. Schematic overview of categories, including subcategories, constituting the overall theme ‘Balance exercise facilitates everyday life’.
Only for the group of participants who started in the late group (n = 26), were falls diaries available from before (weeks 0–7), during (weeks 8–15) and after (weeks 16–24) the balance exercise intervention (n = 22). During the whole study period of 24 weeks they reported in total 245 falls and 2220 near falls, giving a falls rate of 1.28/person/month and a near fall rate of 11.64/person/month. An overall positive, statistically significant trend with a successive reduction of falls was found for the numbers of falls (p = 0.0006) and near falls (p = 0.0018) before, during and after the balance exercise. Mean falls dropped from 4.18 before the intervention to 1.68 after, and near falls from 23.2 before to 8.64 after, as shown in Figure 11. The reduction of falls was also described in the interviews, here by participant 27:

I don’t fall at all now ... not any more, because my core is always engaged.

![Figure 11. Falls and near falls, before during and after the intervention.](image)

Compliance with the supervised exercise was excellent, median 13 of 14 sessions. As to adherence to the home exercise, 48% achieved the goal of performing the home exercise twice weekly. The informants also described in the interviews how they thought that the balance exercise could fit into their everyday schedule without too many alterations. They found the Co-
DuSe balance exercise suitable to target balance. It was considered challenging but still feasible. Although the participants all had different prerequisites and physical functions, they were able to get individual adjustments and recommendations from the physiotherapists leading the balance exercise. This was described as important, since the balance exercise were considered as a brand-new way to approach balance exercise. The participants also expressed how they could use what they had learned in the balance exercise in everyday life, here explained by one of the participants:

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]

Next of kin, study IV
The overall theme of the analysis is ‘Making it work’. This overall theme manifests how the next of kin describe struggling, in different ways in various areas of life, to make it work – making it work for themselves, for the PwMS and for the whole family. The overall theme is constituted by three different themes, where the first two, ‘Taking responsibility’ and ‘Making adjustments’ reflect actions they take to make it work. The last theme, ‘Standing aside for someone else represents what they don’t do, what they renounce, in order to make it work. See overview in Table 5.
Table 5. An overview of the analysis: the overall theme, themes and categories.

Making it work

<table>
<thead>
<tr>
<th>Taking responsibility</th>
<th>Making adjustments</th>
<th>Standing aside for someone else</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being one step ahead</td>
<td>Making practical adjustments</td>
<td>Putting oneself to the side</td>
</tr>
<tr>
<td>Always on the watch</td>
<td>Making emotional adaptations</td>
<td>Abstaining from social activities</td>
</tr>
<tr>
<td>Assisting in daily life activities</td>
<td>Adjusting to a slower tempo</td>
<td>Feeling worried or frustrated</td>
</tr>
</tbody>
</table>

Taking responsibility represents how the next of kin had to take responsibility to a greater extent than before, in different ways and in various areas of life. This was not always a conscious choice, but rather was something they felt obliged by themselves, and sometimes by the PwMS, to do in order to make daily life work. They described how they needed to take on responsibility that they normally wouldn’t have, if the fall risk due to MS was not present.

Yes, there’s a lot of extra things involved, and you have to think. Nowadays, you have to plan your activities. Two years ago, I didn’t have to think so much when we wanted to do something, but in the past two years I’ve been forced to plan and think things through. [Participant 2]

Making adjustments where needed in order to make it work. When planning or trying to foresee possible situations that could result in a fall was not enough, the next of kin described how they needed to make adjustments. The adjustments might not only be conscious choices but also happen unconsciously over time, in striving to make it work. The adjustments
could be practical, such as moving to a new home, rearranging the existing home or changing activities performed, and emotional, such as feelings about rearranged roles in the relationship or how they looked upon life.

We’ve moved, of course. That has meant an enormous change in our physical environment. [Participant 6]

**Standing aside for someone else** represents how the next of kin, despite the adjustments made, were forced to renounce or forego events and activities and to put themselves aside in advance for the PwMS, to make everyday life work. They described how they put being there for the PwMS before their own interests. They also felt obligated to stay at home to keep the PwMS safe from falls. They abstained from social activities, which could cause a feeling of alienation and loss of friends. They also felt worried and/or frustrated over the situation.

Sometimes it can be a bit boring. I’ve lost some friends because I haven’t been able to get together with them the way we always did before. That’s disappointing. [Participant 3]
Discussion

Major findings
People with MS fall in the course of everyday life activities, most often in their own homes due to various intrinsic and extrinsic factors. Balance can be improved, falls reduced and everyday life may be made easier and facilitated after participating in the CoDuSe balance exercise. This is important also for next of kin, since they are adapting, adjusting and renouncing their activities due to the falls of the PwMS, in order to make it work for the whole family. The results of all studies are shown in Figure 11 below.

Figure 11. Overview of the results of this thesis.

Fluctuations of symptoms may occur within and between days. Fluctuating symptoms within a day make it difficult for PwMS to know their physical abilities at that specific moment in a particular activity that could cause a fall.
By participating in balance exercise including core stability, dual task and sensory strategies, dynamic balance can be improved and the number of falls reduced. Taking part of the CoDuSe balance exercise was considered to facilitate everyday life in different aspects. The participants described how they learned to activate their core muscles and how they could activate them in everyday life activities. This made them feel more confident in the body, since they could control it. Having this control made their activities safer and easier to perform, leading to increased independence and participation in daily living.

Falls by PwMS also affect the next of kin, who have to take a greater, different responsibility over the relationship and the family. They have to adapt, both practically and emotionally, to the fact that the PwMS occasionally falls. When adaptation is not possible, they need to curtail their own activities and stand aside for the PwMS, in order to make everyday life work.

**Fall situations in PwMS**

The novelty of the data in study I is that the information was collected immediately or very soon after the falls occurred.

As reported in the results of the present thesis, 85% of the informants fell during the study period. This finding confirms the fall frequency to be high, as previously reported in an international meta-analysis; however, that study reported a slightly lower fall frequency, 56%. A possible explanation for the difference could be the higher EDSS score in the present thesis (5.9 vs 4.3). The fact that the informants in the present thesis reported the falls as occurring most often in their own homes while performing everyday life activities could be an expression that much of the time is spent at home. A higher EDSS score could mean that they are less actively involved in out-door activities in society. People with a lower EDSS score had a higher frequency of falls outdoors. Most of the falls were reported to occur during basic ADL, such as transferring, walking or engaging in personal hygiene. Moving around in the home and transferring are activities frequently performed. For example, rising up from a chair and sitting down again has been reported to be performed approximately 50 times a day by community-dwelling adults, making it an activity impossible to stop doing. Adjustments can be made, and strategies to perform transfers from sitting to
standing can be created; however, PwMS can’t completely stop performing them. Falling during general mobility activities or during transfers and walking has also been described previously. Only 14 of the 67 included informants were still working, also a possible reason for more time spent at home. Of the 14 informants still working, 12 reported falling during the study period. Still, only three of the falls were reported to occur at work. Undertaking extra safety precautions to guard against falling in the company of coworkers, and possibly with others in public places (i.e. outdoors), is a possible explanation. Another possible explanation is that PwMS feel more comfortable in their own homes, making them less wary in their activities and movements.

The informants described how it was perceived as important to keep performing their everyday chores, such as household work or other domestic chores. This underlines the importance of evaluating the risk factors for falls for each individual, to maintain the ability to be active in everyday life. A review by Quinn et al. concluded that clinical outcome measures have poor predictive ability for fall risk in PwMS, stressing the importance that the team of health care professionals around the PwMS needs to identify potential fall risk factors for each individual.

The intrinsic factors often interacted with each other, making it difficult to determine one single explanation for the fall. Intrinsic factors were more frequently reported than extrinsic factors. The fact that the fall risk fluctuates over time is previously known; however, the results in this thesis suggest that it also fluctuates within a day; a fluctuation that could be instantaneous within a day is a new finding. The intrinsic factors might be related to the three balance difficulties (delayed response to postural perturbations, increased sway in quiet stance and reduced ability to move towards limit of stability) described in a review as causing falls, with the addition of the dual-task problematics. They can also be related to static, dynamic, proactive and reactive balance.

Cognitive function has previously been related to fall frequency in PwMS, as well as the need for dual tasking. One strategy to compensate for impaired balance is to use walking aids; however, this requires dual tasking. The literature has been inconclusive when it comes to the use of walking aids. While some studies have reported the use of walking aids to be a risk factor for falls, PwMS have reported the use of walking aids as
helpful in maintaining balance.\textsuperscript{49} The majority of the informants in the present thesis described their walking aids as facilitating rather than hindering them in everyday life. However, a vast minority received actual practice in how to use their new walking aid when it was prescribed, and no one received practice in the environment in which the aid was intended to be used. Since walking aids were used incorrectly in 24 of the 35 falls where the walking aids were present, it seems important to ensure correct adjustment of the walking aid, as well as to offer practice in optimal and functional use of the walking aid. Clinicians prescribing walking aids should be aware of the importance of optimizing the use of a walking aid, with the aim of reducing falls. Thorough follow-up on prescribed walking aids, by the prescribing physiotherapist within the healthcare system, is warranted. To reduce risk of falls, both intrinsic and extrinsic factors must be targeted.

\textbf{CoDuSe balance exercise}

The CoDuSe balance exercise reduced the number of falls, as both measured with the study-specific fall diary and described by the participants themselves in the interviews. The falls also, as shown in this thesis, reflect on and affect the lives of their next of kin. The fact that the CoDuSe balance exercise reduced the number of falls is in line with previous evaluation of the CoDuSe intervention,\textsuperscript{92} where both fall frequency and number of fallers were reduced. It is also in line with previous research indicating that the number of falls can be reduced with exercise.\textsuperscript{81}

Balance, measured with BBS, was statistically significantly improved after the CoDuSe balance exercise in participants compared to the controls, results that are in line with previous results where balance has been described as improved for PwMS with mild to moderate MS after participating in the CoDuSe balance exercise.\textsuperscript{91} BBS was chosen as the primary outcome measure, a measure that contains items challenging both static and dynamic balance.\textsuperscript{113} Almost all of the items contain movements or challenges that were described as having influenced the fall situations in the interviews included in this thesis (\textit{study I}), such as reaching forward, picking up something from the floor or enacting a 360° turn. Besides statistical significance, clinical relevance of changes should be pondered. Minimal detectable change for the BBS has been suggested to vary between 3 and 7.\textsuperscript{116,142} The studied samples vary in size (n = 24–120) and in EDSS score (0–6.5). A study investigating sensory integration rehabilitation with an EDSS median of 3.0 used the minimal detectable change of three points.\textsuperscript{143} Since the included sample
of the present study had a higher EDSS median (6.0), and 89% were expected to have a progressive MS, we therefore settled for a three-point change, which was exceeded.

The participants described an improvement in core stability as well as walking ability, in the interviews but not in the objective outcome measures. The secondary outcome measures evaluating core stability or walking ability all included time elapsed, which can be a possible explanation for the differences. The focus of the balance exercise was to activate and control the core muscles and then to maintain focus on the core stability while performing the remaining exercises, hence, making controlled movements. Evaluating that with outcome measures based on time could be one reason why there were no differences between the groups. Lack of statistically significant improvement in the outcome measures evaluating time may be due to the fact that the participants became better and more thorough in the execution, not faster. Since there are various individual factors that influence each individual, an outcome measure suitable for each individual in this group of people can be challenging to find. This also stresses the importance of asking the participants to describe their own experiences after taking part in a balance exercise like this. The complementary results of the two studies indicate the importance of using both qualitative and quantitative evaluations of an intervention.97, 99

Interviewing the participants after the CoDuSe balance exercise intervention captured thoughts on how their everyday lives were affected. They received a new awareness on how to control the core muscles while performing functional tasks that required dual-task or sensory strategies, which were considered important for them. Even though the evidence for core stability exercise in PwMS has been equivocal,86, 91, 96 the participants in this thesis perceived that the balance exercise containing core stability as one component made them feel safer while performing various ADL. They described how feeling safer facilitated their activities and enhanced their perceived participation, an important effect, since previous studies have reported participation to be restricted amongst PwMS,52, 53 a restriction that increases with disability level.52 Both avoidance of social activities and isolation are associated with lower health-related quality of life, while high health-related quality of life is associated with social participation.144 The importance of enhancing participation for PwMS, especially those with a higher EDSS, is therefore of great value.29
Notable is that the participants described how they could be more active, and have a greater participation, while at the same time they described how they did not need to use walking aids to the same extent after taking part in the balance exercise. Activity limitations have been reported to influence the probability of using a walking aid. At the same time, it has been reported that use of walking aids can diminish activity limitations. Results in the present thesis show that walking aid use does not automatically mean increased activity level. After participating in the CoDuSe balance exercise, the participants described how they were more active and how they used walking aids to a lesser extent. They described how they felt more confident, giving them a feeling of trust in their ability to accomplish tasks that they had not been able to manage before. The balance exercise possibly generated self-confidence in the activities that the walking aid could not.

The participants described the CoDuSe balance exercise as affording a new awareness of the core muscles and found the content suitable for targeting balance. They also described the balance exercise as feasible and challenging. Facilitating factors for exercise in PwMS have been reported to be both environmental and personal. The CoDuSe balance exercise was performed in groups, but the balance exercise was still individually adjusted based on the participants’ own abilities. Exercising in these groups gave the peer support and social interaction described as facilitating for physical activity, but still allowed the exercise to be individually tailored to each participant, which has also been described as facilitating. It has been reported that it is important to individualize the exercise for the neuroplasticity to be optimal for each participant. When the exercise is led by a knowledgeable and skilled physiotherapist with previous experience in MS, the likelihood that the movements are correctly performed is enhanced. The participants described how they could get feedback and guidance from experienced physiotherapists regarding the control, the intensity and the progression of the exercises, based on their own physical ability.

**Next of kin**

Next of kin are affected, in terms of adjustments and responsibility, by the fact that their cohabiting relative falls, but they are also forced to sometimes stand aside for someone else. They are determined to make their mutual life together work. This is described by the next of kin, but it involves and affects them also as a couple and as a whole family. It has previously been
described how MS being a neurological disease affects the whole family. The results of the present study reveal that, besides MS in a broader perspective, falls specifically, have an impact on the next of kin to PwMS.

The participants in the present study were next of kin who had chosen to stay in a relationship or to continue cohabiting with a parent. They described how, due to the fact that the PwMS experience falls, they in a sense came to surpass the PwMS, at least physically, and sometimes cognitively, making them no longer equal in the relationship. Changes in the relationship with a PwMS have previously been described by next of kin as a consequence of MS as a whole. The relationship has been described as more care-based after the diagnosis, and the probability of remaining in a relationship compared with a relationship between two healthy people has been reported to be significantly diminished. A Danish study showed that the probability of remaining in a relation after 24 years where one of the partners had MS was 33%, compared to a 53% probability in the healthy controls. It has been reported that when the woman in a heterosexual relationship is diagnosed with a severe disease (e.g. cancer, brain tumour or MS) there is a six-fold increase in risk for a separation, compared to when the man is diagnosed. Since MS is more common in women then in men, a higher separation rate is possible. As the present study confirms the next of kin having to take on an increased responsibility when the PwMS begins to fall, which alters the roles in the relationship, it is important for the healthcare system to offer emotional support, including to the next of kin.

The next of kin described how they needed to adapt themselves and adjust their lives to make the situation as well as the relationship work. They have previously described how it is important to receive ongoing information about the disease from the healthcare professionals. Since next of kin take on great responsibility as well as making adjustments and sacrifices to deal with and prevent falls, such information could, and should, include facts about falls and preventive strategies.

When a person is first diagnosed with MS, it is possible that not only the PwMS but also the next of kin could end up in a phase of shock and neglect their own needs and suppress their feelings initially. The interviews in the present study were conducted long after the initial phase, the PwMS and the next of kin having had time to build up a joint everyday life in the family. During the interviews it became clear that the next of kin were not
accustomed to being asked about their own feelings and thoughts. They often slipped into discussing the PwMS and their needs instead. They described how they were never asked about themselves by family, friends or healthcare staff: all focus was on the PwMS. To ask the question to a next of kin, ‘Tell me how that is for you?’ is in itself of new value. It seems important to give the next of kin room for their thoughts and feelings, something to consider within the healthcare system. The results also indicate that their renunciations of their own needs and priorities, their leisure activities and their social lives in favour of the PwMS continue after the initial phase because of the occasional falls experienced by the PwMS. Next of kin of PwMS have also previously reported decreased freedom and curtailed independence, as have the next of kin of people with other diseases, such as cancer or muscular dystrophy. It is possible that the results of the present study may not be specific to MS, but could also be relevant to other diseases with increased risk for falls.

Previous research has shown that spouses experience a gain in independence when their partner with MS is engaged in exercise. The spouses described that the exercise gave their partner with MS improved physical functions, which could reduce their caregiving responsibilities. As the next of kin described in study IV, they felt an increased responsibility and a need to put themselves aside for the PwMS. Given the fact that the CoDuSe balance exercise improved the participants’ balance and reduced the number of falls, it is possible that the perceived effects from taking part in the balance exercise (study III) also could have positive effects for their next of kin in their everyday lives.

**The complexity of balance and falls**

As stated throughout this thesis, both balance and falls are complex phenomena to describe. The results in this thesis could be understood by the components in the ICF framework. The factors associated with falls in study I, could be described in terms of body function and structure, activities, participation, personal factors and environmental factors.

By exercising in the CoDuSe balance exercise (studies II and III) the participants improved their body functions, and enhanced and eased their activities, which led to an improved participation. Their self-confidence was described as being improved, indicating that the personal factors can be af-
fected by the balance exercise. The balance exercise also affected the envi-
ronmental factors, as in the ability to stay active with less support from
other people as well as from walking aids.

The next of kin play an important role in making everyday life work
(study IV). The next of kin can be classified as environmental factors. They
may also make the activities more readily available, which enhances the
ability of PwMS to participate.

**Methodological considerations**

The results in this thesis are based on data collected using different methods:
telephone interviews (study I), quantitatively measured outcomes (study II)
and face-to-face interviews (studies III and IV). It is important to take the
strengths and the limitations of the studies into consideration. Using trust-
worthiness is a way to consider qualitative research. The concept was intro-
duced by Lincoln and Guba\textsuperscript{155} and consists of four criteria: credibility, de-
pendability, confirmability and transferability. In quantitative research the
terms validity and reliability are more commonly used when talking about
the quality of the research. The strength and limitations of the thesis are
discussed using these terms below.

**Credibility and internal validity**

Credibility in qualitative research is roughly equivalent to internal validity
in quantitative research. Credibility and validity deal with the focus of the
research and how well the intended focus is addressed; they ensure that the
study actually measures or tests what it intends. Establishing credibility is
especially important in qualitative research, as the researcher is a major in-
strument of data collection and analysis.\textsuperscript{156} Ensuring credibility is one of the
most important factors when trying to establish trustworthiness.\textsuperscript{155}

To establish credibility (studies I, III and IV) and internal validity (study II),
the study populations were carefully selected. All studies recruited partici-
pants or informants from several different centres, making the data collec-
tion multicentre. In study II, the Swedish Neuro Register was used in com-
bination with personal knowledge by the clinical physiotherapist in charge
of the research intervention at each centre, to identify eligible participants.

To be registered in the Swedish Neuro Register is voluntary; hence the grade
of coverage is not perfect.\textsuperscript{157} The grade of the Neuro Register is, however,
considered to be high, 76%.\textsuperscript{158} Nonetheless, it is not known to what extent
the EDSS score is updated by the patient’s neurologist. To be able to choose
the participants for the interviews after the CoDuSe balance exercise, a purposeful selection were made to mirror the whole group. Sex, age, centre and disease burden were taken into consideration to achieve variety. An enhancing factor for the credibility is that there is no selection within the selection in study III, since all invited participants accepted to undertake the interviews. A consecutive sampling was used in study IV, by asking informants in study I for permission to contact their next of kin. By enrolling next of kin using this method, we could be assured that the PwMS actually had experienced a fall, strengthening the credibility. All but two accepted participation, also strengthening the credibility. During the interviews in study IV, the next of kin sometimes talked about other symptoms or situations related to MS as a whole. While we were unable to completely distinguish experiences related to falls from experiences of the whole situations, during the interviews participants were always led back to focusing on falls and fall-related situations.

A limitation in the data collection, possibly threatening the credibility, is the fact that participation was voluntary (studies I–IV). However, it is not ethical to include involuntary participants or informants, and it has been argued that only those who are genuinely willing to freely take part should be included.159

In study III the results may have been affected by the fact that the interviews were conducted by A.C. Some of the participants had already come into contact with A.C. during study II, either in the role as leader of the intervention (one centre) or as the physiotherapist in charge of the measurements (four centres). It is important to consider that serving as both researcher and study leader may have biased the responses.

The interviews in studies I, III and IV were transcribed by a secretary, and the transcripts were thereafter read through by A.C. while simultaneously listening to the recorded interviews. According to Shenton, this is another way to increase the credibility of the results.159 To strengthen the credibility during the data analysis, an interactive process between the researchers (studies I, III and IV) was undertaken until consensus was reached.155 To further enhance credibility, representative quotations were selected in the three qualitative studies. During the work of this thesis peer scrutiny of the research project was undertaken in the form of seminars, also a factor that increases credibility.159
The outcome measures in study II were chosen to reflect different aspects of balance. Since the focus of the CoDuSe balance exercise was to find and maintain core stability, the focus of the outcome measure could have been chosen more carefully. All outcome measures including walking (three outcome measures) included the factor of time. Since it was the quality rather than the quantity that the balance exercise aimed to improve, it would have been suitable instead to use other outcome measures focusing on quality of movement and walking.

**Dependability and reliability**

Dependability in qualitative research is comparable to reliability in quantitative research. To achieve dependability, it is important to present the method as thoroughly as possible, since it is important that future researchers are able to repeat the results using the same methods, in the same context and with the same sample. Dependability represents stability of data over time. Dependability of the results can be increased when the researcher is consistent when collecting and analysing the data.

Interview guides were used during all interviews, studies I, III and IV, to establish dependability. The interview guides were used as a tool/checklist to cover all areas warranted; however, it was the interviewees themselves who controlled the interviews through what they were willing to share. A limitation of study I is that there is no guarantee that the informants actually did call to report when they experienced a fall. Using body-worn monitors would possibly give an increased accuracy of the fall frequency. However, the interviews would still be needed to determine what caused the falls, during which activities and where they occurred.

There were four physiotherapists who were raters during the measuring occasions in study II. Each participant was always measured by the same physiotherapist. To ensure inter-rater reliability, prior to study start, the raters were trained in order to minimize systematic differences in rating and measuring the participants’ performance. All raters also had a study protocol, so that all tests were conducted in the same order, using the same instructions.

**Confirmability/objectivity**

Confirmability in qualitative research is equivalent to objectivity in quantitative research and describes how the results should reflect the experiences
of the participants and not the perceptions of the researcher.\textsuperscript{155} The researcher’s preunderstanding of a context can be seen as a limitation, as it threatens the confirmability.\textsuperscript{156} However, it can also be considered a strength, since a preunderstanding could make it possible to capture circumstances influencing complex fall situations in study I. Using a tape recorder during all interviews in studies I, III and IV strengthens the confirmability. In study I there was a short time between when the fall happened and when the interview took place, minimizing recall bias. In an RCT study, it is preferred that the study is blinded to achieve objectivity. In an intervention study such as that evaluated in studies II and III, it is impossible to blind the participants, since there is no way to blind them to whether they are participating in the exercise or not. However, the raters were blinded to which group the participants were allocated to. By using falls diaries, the participants reported falls during the study period. It is possible that not all falls were registered, hence a potential bias. The reductions of falls were verified by the following interviews. Using interviews as a way to evaluate a balance exercise (study III) gives the participants an opportunity to express in their own words the effects of the exercise, rather than being limited by what the researcher may think possible to affect (when choosing outcome measures).

**Transferability/generalization**

Transferability or generalization concerns the extent to which the results from one study can be applied to other situations, persons and populations. Having data collected from different centres enhances both the transferability and generalizability, since the participants and informants lived in different settings. Both urban and rural areas were included, and the different centres represented six different county councils/regions at different care levels.

Both women and men were included in all four studies and their demographic data were presented in all four studies. Using EDSS scale to describe disease burden in studies I, II and III strengthens the transferability of the results to similar populations.

In the CoDuSe balance exercise intervention (studies II and III) there were no restrictions due to the type of MS, which also strengthens the transferability. The numbers of physiotherapists leading the CoDuSe balance exercises in the different centres can be a strength, since the intervention is not
about just one person but several. This makes is possible for other physiotherapists to implement the balance exercises in their clinical settings. However, using several different physiotherapists can also be seen as a limitation, since there is no guarantee that all were doing exactly the same, even though an extensive interactive process was performed together with all participating physiotherapists before the intervention.

Using home exercises is likely to be of great value in maintaining gained abilities, and the transition from the group exercise with help from leaders to individual exercise responsibility at home was initiated early. Having a strategically selected sample in study III strengthens transferability.

**Future studies**

Several studies have tried to determine why PwMS fall. Using interviews for data collection, immediately or soon after the fall occurs, can give valuable information. It is well known that impaired balance and also falls often occur in the beginning of the disease. Using a similar design as in study I of this thesis, but including people with a lower EDSS score (<3.0) would give additional information regarding when and why these people fall. Looking closely at patterns of falls and investigating why they occur would also be of great value in developing individual fall preventive strategies. Mazumder et al.\(^{160}\) have reported differences in when PwMS fall compared to healthy controls, in a rather small cohort using falls diaries. It would be of interest to include a larger sample of PwMS and collect data through interviews over the whole year, including all the different conditions connected to the four seasons.

As reported in study I, PwMS often fall at home. It would be of great interest to conduct balance exercises with the purpose of reducing the number of falls in the same environment as they live in. This would also give the opportunity to evaluate whether adjustments in the home environment need to be taken into consideration. Since many of the falls occurred even though a walking aid was involved, it would be of interest to prescribe and offer training with the walking aid in the environment in which it is meant to be used. Would this reduce the number of falls that occur while using a walking aid?
Practice getting up from the floor is common in physiotherapy. It could be valuable to include next of kin in this practice and evaluate whether they feel empowered when assisting a PwMS in an actual fall situation.
Conclusions

Falls occur mainly indoors during basic activities. Several influencing factors, both intrinsic and extrinsic, interact in each fall situation. Fluctuating bodily symptoms of MS make it difficult to know a person’s current capacity for the activity performed. Fluctuating symptoms within a day have not previously been described as a factor that causes falls. The gap between what the individual is physically capable of and the demands both of the activity performed and of the environment creates a fall risk, especially when divided attention is needed to succeed in the task. Rehabilitation professionals should target both intrinsic and extrinsic factors to reduce fall risk. Walking aids were not described as causing the fall situations; however, they were often involved in the falls. If not used as intended, walking aids cannot prevent a fall. A structured prescription and exercise as well as thorough follow-ups on prescribed walking aids are warranted.

The CoDuSe balance exercise seems promising in improving dynamic balance and reducing perceived walking limitations compared to the control group. It also reduced frequency of falls and near falls.

Participation in the CoDuSe balance exercise was perceived to facilitate everyday life among PwMS. They acquired new awareness of how to use their core muscles to facilitate ADL, 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. Using the CoDuSe balance exercise could be a tool for physiotherapists to improve balance, reduce falls and facilitate everyday life for people with moderate to advanced MS. It is a balance exercise programme conducted in groups, feasible for PwMS.

Not only PwMS are affected by the fact that they fall; next of kin are also affected in their everyday lives. To keep their relatives from falling, next of kin take on increased responsibility and try to adapt their lives both practically and emotionally to make the situation work. Yet, their adaptions are not always enough. When adaption is not possible, next of kin put themselves and their time aside in favour of the PwMS to make life at home work. The next of kin can also need both practical and emotional support from the healthcare system to help them take care of themselves while managing to live with, care for and protect the PwMS from falls. Highlighting the fact that next of kin also are affected by the falls of their cohabiting...
PwMS enhances the importance of fall prevention activities that should include the next of kin. Enhanced information from the healthcare system can empower and help them to take care of themselves while managing to live with, care for and protect the PwMS from falls.
Sammanfattning på svenska


Avhandlingsarbetets övergripande syfte var därför att få en ökad kunskap om när och varför personer med MS faller (delstudie I) och hur detta eventuellt påverkar deras anhöriga (delstudie IV), samt att utvärdera effekten och upplevelsen av vad det ger i vardagen att delta i en specifik balans träning (delstudie II och III).

I intervjuer med 57 personer med MS beskrevs 115 fallsituationer där det framkom att fallen oftast uppkom inomhus och under vardagliga aktiviteter. Det finns ofta en interaktion mellan olika inre och yttre faktorer i en fallsituation, vilket gör det svårt att urskilja en enskild utlösende faktor. Inre riskfaktorer som framkom var MS-relaterade symtom, fluktuerande symtom, distraktioner samt förlorad kroppskontroll medan yttre riskfak-
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Inre riskfaktorer beskrevs vara mer vanligt förekommande och mer utslagsgivande än yttre. Fluktuerande symtom inom och mellan dagar gör det svårt för personer med MS att i varje stund veta sin kapacitet. Glappet mellan personens faktiska kapacitet och de krav som ställs för att kunna utföra en viss aktivitet inklusive omgivande faktorer leder till ökad fallrisk. Särskilt tydligt är detta i situationer då delad uppmärksamhet krävs.

I en randomiserad kontrollerad pilotstudie inkluderades 51 personer med mer uttalad funktionsnedsättning relaterat till MS med syftet att öka balansen och minska antal fall. Studien hade en vänte-listdesign vilket innebär att deltagarna randomiserades till att träna med tidig eller sen start. Deltagarna som hamnade i gruppen med sen start agerade kontroller till deltagarna med tidig start. En gruppträningsintervention innehållande tre delar; bålstabilitet, aktiviteter som kräver delad uppmärksamhet och/eller sensoriska system (kallad CoDuSe) utfördes en timme, två gånger i veckan under sju veckors tid utvärderades. De första 30 minuterna var träningen fokuserad på bålstabilitet. Deltagarna uppmanades därefter att behålla bålkontrollen medan de utförde övningar som krävde att de använde sig av delad uppmärksamhet (t.ex. gå och samtidigt balansera en bricka med ett glas, bolla ballong under uppresning) eller sensoriska strategier (t.ex. gå på varierat underlag, blunda eller minska understödsytan). Träningen utfördes i grupper om 2-5 deltagare men var individuellt anpassad och kontinuerligt anpassad till varje deltagare med sjukgymnastens/fysioterapeutens hjälp. Varje deltagare fick också två till fem individuellt utprovade övningar att göra hemma och en träningsdagbok. Efter interventionen genomfördes 27 intervjuer med strategiskt utvalda personer för att utvärdera de upplevda effekterna av träningen i vardagen.

Den dynamiska balansen, mätt med Bergs Balansskala (primärt utfallsmått) förbättrades statistiskt signifikant i träningsgruppen (p = 0.015), jämfört med kontrollgruppen. Även den självupplevda gångfunktionen, mätt med Gångskala vid MS nådde nära signifikans (p = 0.051). Övriga kvantitativa utfallsmått visade ingen statistisk signifikant skillnad mellan grupperna. Antal fall minskade från 4.18 före balansträningen till 1.68 efter balansträningen. Den minskade fallfrekvensen verifierades i intervjuerna efteråt. I intervjuerna berättade deltagarna även hur de av balansträningen fick ökad kontroll av sin bålmuskulatur, vilket ledde till att de kände sig mer säkra i sin kropp och de fick ett ökat kroppligt självförtroende. Att de kände sig
säkrare innebar att deras aktiviteter blev lättare att utföra, vilket ledde till en ökad delaktighet och minskat användande av gånghjälpmedel. De upplevde att effekten av träningen underlättade i deras vardag.

För att beskriva om och hur anhöriga som bor tillsammans med personer med MS som stundtals faller upplever detta intervjuades 20 anhöriga. De anhöriga beskrev hur de på många olika sätt och på olika plan i livet ändrade och justerade för att få vardagen att gå ihop. De beskrev hur de fick ta ett ökat ansvar över olika områden i livet. De ökade ansvaret var inte alltid ett medvetet val utan något som de ålade sig själva att ta för att få vardagen att gå ihop. De var tvungna att planera, att ständigt vara beredda att agera samt hjälpa till i vardagliga situationer. De berättade även hur de var tvungna att göra anpassningar för att få vardagen att fungera. Anpassningarna var både av praktisk och emotionell karaktär samt att de var tvungna att anpassa sig till ett lägre tempo, för att passa personen med MS. När anpassningar inte var tillräckliga för att få ett gott och funktionellt liv tillsammans med personen med MS så var de anhöriga tvungna att göra avkall på sig själva för att få vardagen att fungera. De satte sig själva i andra hand för att ge plats till personen med MS samt avstod från sociala aktiviteter. Detta kunde leda till känslor av oro och frustration.

Personer med MS faller i vardagliga aktiviteter, där fallen beror på både inre och yttre faktorer. Genom att träna enligt CoDuSe så kan balansen förbättras och antal fall minska. Balansträningen kan även underlättat vardagen för personer med MS. Inte bara personen som faller påverkas av detta, även anhörigas vardag påverkas av det faktum att personer med MS ibland faller. För att förhindra fall så försöker anhöriga ofta få vardagen att fungera för personer som faller på grund av MS genom att ta ett ökat ansvar, göra justeringar samt göra avkall på sig själva.

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